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ABSTRACT

This manual is intended for administrators and professional caregivers who wish to provide comprehensive health care to children with Human Immunodeficiency Virus (HIV) infection, the cause of Acquired Immune Deficiency Syndrome (AIDS). Chapter 1, an overview, examines the societal and economic issues that affect care and treatment of children infected with HIV. Chapter 2 describes five key components of pediatric HIV/AIDS programs: long-term planning for chronic illness; child-centered and family-focused approach; interdisciplinary, collaborative care; case management; and community support. Chapter 3, "Mobilizing for Program Organization," is a step-by-step guide to establishing a program of care through assessment, planning, implementation, and evaluation. Chapter 4 provides extended descriptions of the 10 hospital pediatric HIV/AIDS programs throughout the country from which information was gathered to produce this manual. Appended are the following resources: (1) official definitions and classifications of HIV-related diseases; (2) community assessment guide; (3) a list of state AIDS coordinators; (4) an outline of critical program components through the continuum of care; (5) a list of resources for service providers including AIDS clinical trial units, demonstration projects, organizations, audiovisuals, literature, and telephone contacts; and (6) a listing of the 10 highlighted programs. (TE)

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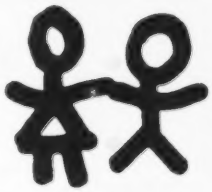
CHILDREN WITH HIV/AIDS

A Sourcebook For Caring



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A Guide for Establishing Health Care Services for HIV-Infected Children

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Children With HIV/AIDS: A Sourcebook For Caring

A Guide for Establishing Programs for Children

by

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This book was produced as a project of the National Pediatric HIV Resource Center, 15 South Ninth Street, Newark, NJ, (201) 268-8273. The Center's goals are to provide health care professionals with information and materials for patient and family education about pediatric HIV infection; guidance regarding organization and delivery of health care services; assistance in developing community-based services for HIV-infected children; and consultation, legal, and technical assistance to organizations involved in the care of HIV-infected children.

Support was provided by the National Pediatric HIV Resource Center, Children's Hospital of New Jersey and the New Jersey Department of Health, through project # BRH P 02011-01-0 from the Bureau of Maternal and Child Health and Resources Development (Section 301, Public Health Service Act), Health Resources and Services Administration, U.S. Department of Health and Human Services.

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Introduction

Many children's hospitals and pediatric units around the country have been encountering and struggling with the complex health and social needs of children infected with the Human Immunodeficiency Virus (HIV), the cause of Acquired Immunodeficiency Syndrome (AIDS). Many sought initial help from the National Association of Children's Hospitals and Related Institutions, Inc. (NACHRI). They asked: What problems should we anticipate? How should we become equipped? Who else is experiencing this new health problem, and what are they doing about it?

As NACHRI staff examined these questions, it found no single source of information on how or what to do to organize care for children with HIV infection. Some answers to these questions existed for adults, but literature for care of children was minimal. Therefore, NACHRI determined to set about acquiring child-related HIV/AIDS information and preparing it for dissemination.

The result is the *Sourcebook For Caring*, a manual for professionals who wish to provide comprehensive health care to children with HIV infection. It is written for administrators who design and organize programs, and for the many caregivers who actually touch the young lives of HIV-infected children and their families. Child-centered and family-focused in its approach, the *Sourcebook* identifies the critical elements required for hospital and community-based programs that will meet the complex health and psychosocial needs of children with HIV/AIDS. It describes the work being done across the country in areas of high pediatric AIDS incidence and provides recommendations from health care providers and administrators experienced in this type of care. This information is documented here for ready access and use so that others may benefit from the practical experience shared by the professionals working in these programs. It is with the willing cooperation of the involved health care providers and administrators that this work has been facilitated.

The information contained in this *Sourcebook* was obtained through literature review, telephone interviews and site visits with professionals who provide care for children with HIV infection. To determine the extent of hospital involvement with children with HIV infection, a survey of 19 hospitals revealed that indeed children were receiving care in hospitals. Of the 19 hospital programs surveyed, 10 of the larger ones were selected for site visits to illustrate both variety and experience in program implementation.

The ten programs include:

- Adolescent AIDS Program at Montefiore Medical Center, Bronx, New York
- Pediatric AIDS Program at Harlem Hospital Center, New York, New York
- Children's Hospital AIDS Program (CHAP) at Children's Hospital of New Jersey, Newark
- Mt. Washington Pediatric Hospital, Baltimore, Maryland
- Special Immunology Service at Children's National Medical Center, Washington, DC
- Pediatric AIDS Health Care Demonstration Project of the South Florida AIDS Network at Jackson Memorial Hospital, Miami
- Maternal Infant Center for HIV (MICH) program at Children's Hospital of Michigan, Detroit
- Special Infectious Disease Clinic at Children's Memorial Hospital, Chicago, Illinois
- Los Angeles Pediatric AIDS Network at Childrens Hospital of Los Angeles, California
- HIV Clinic at the Children's Hospital, Oakland, California.

The *Sourcebook* is divided into four chapters. Chapter 1 discusses the current knowledge about pediatric HIV/AIDS in children and the societal issues that affect care of these children. Chapter 2 highlights the critical elements common to the model programs. Chapter 3 describes how to initiate or expand a program of care for HIV-infected children. It charts the steps necessary to mobilize for program organization and describes how to take them. It is organized to address four of the key disciplines necessary to create a comprehensive program: administration, medicine, nursing and social work. Chapter 4 describes the unique features of these programs in action and addresses each program's hospital, community, evolution, size, structure, and finances. □

Chapter One

Overview of HIV Infection in Children

This chapter briefly examines the societal and economic issues that affect the care and treatment of children infected with HIV. Caregivers, administrators and public relations specialists, who understand how HIV infection impacts a child's and a family's life, will be better able to justify, plan and implement a pediatric HIV/AIDS program.

HIV infection affects the family, the community and society at large. Responsibility to care for HIV-infected infants, children, and adolescents rests with each one of us: with the family, which cares for a child with multiple and complex needs; with the health care provider who identifies the child with HIV infection and provides the coordination, care, and follow-through for the many needs resulting from the infection; with the community, which provides facilities and caregivers; with the government, which pays most of the bill of HIV-infected children; and with society, which must begin to teach, model and advocate change in behavior so that the spread of HIV infection is prevented.

This *Sourcebook* will not serve as a reference on the clinical aspects of HIV infection in children. Clinical information about HIV infection is changing almost daily and any specific clinical information provided here would likely become dated in a short time. Relevant references for the clinical management of HIV infection in children are contained in the reference sections following each chapter.

Epidemiology

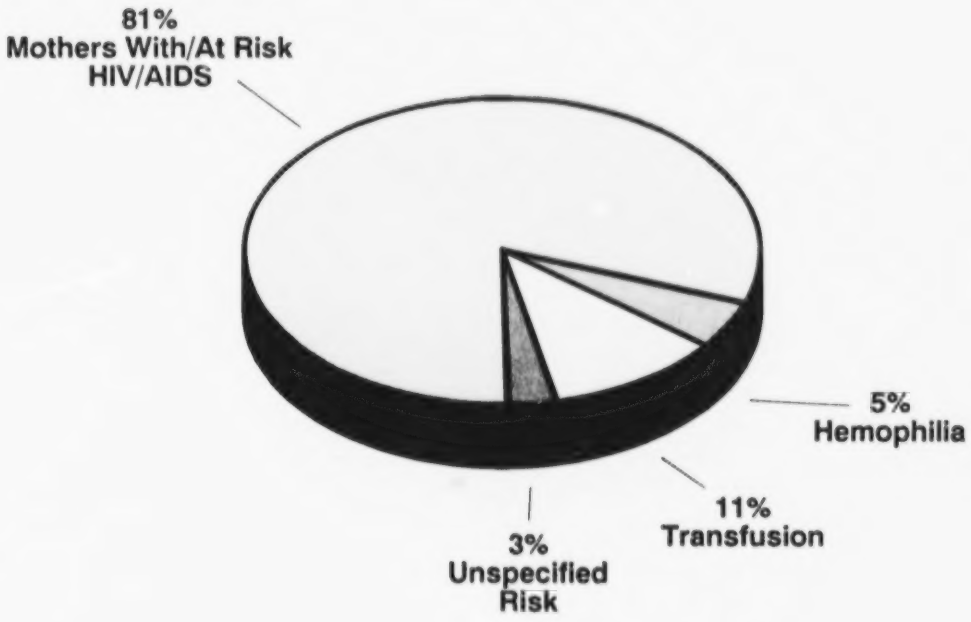
In the United States, most of the initial cases of AIDS occurred in homosexual men and recipients of blood or blood products. Subsequently, AIDS was noted in intravenous (IV) drug using individuals, including women. It was soon recognized that heterosexual transmission could occur, with male-to-female transmission apparently being more efficient than female to male.[1] Nationwide, the percentage of women with

AIDS doubled between 1986 and 1988 to nearly 7 percent of the total number of cases. New demographic studies have shown that AIDS in women, especially in those of childbearing age, is increasing dramatically. As of mid-year 1989, women with AIDS comprised nearly 11 percent of the total number of cases.[2]

Most of the early reported cases of pediatric AIDS were acquired as a result of transfusion of HIV-contaminated blood or blood products, especially in hemophiliacs. That group of children is generally school-aged; many now in their teens. Children with hemophilia are well integrated into the health care system and their numbers are not expected to grow since blood system safeguards are in place. With the introduction of HIV screening of blood and donors and the improved processing of clotting factors in 1985, this route of transmission has been virtually eliminated in the United States.

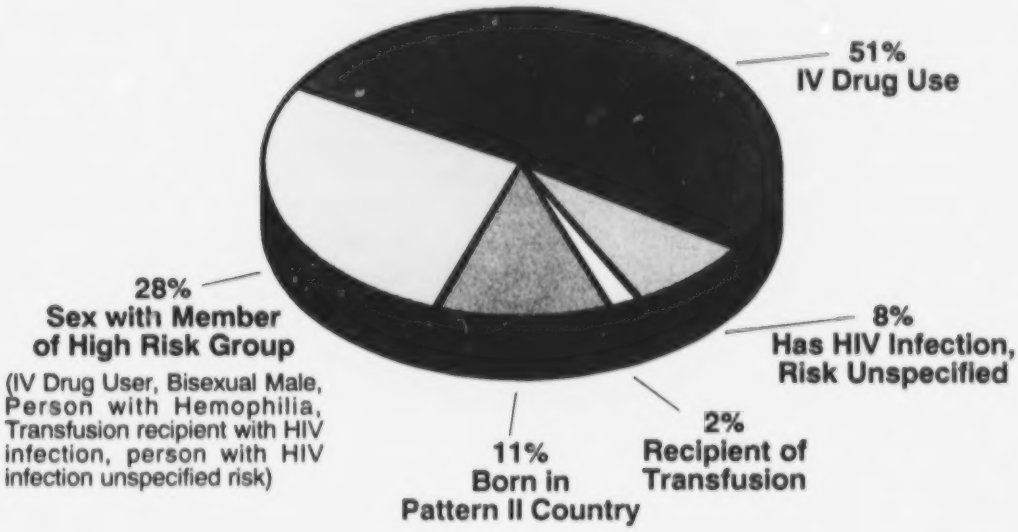
Today, there are about four times as many infants and children infected during or after pregnancy or delivery (vertical or perinatal transmission) as there are from blood and blood product transfusions, and unspecified causes combined (Figure 1-1). Of those infants infected perinatally, more

Figure 1-1. Cumulative Pediatric AIDS Cases (<13 y.o.), by Exposure Category, Through November, 1989



(Source: Centers for Disease Control. (December 1, 1989) HIV/AIDS Surveillance: Cases reported through November, 1989, Atlanta, GA, U.S. Public Health Service)

Figure 1-2. Cumulative Perinatally Transmitted HIV/AIDS Infection, by Exposure Category, Through November, 1989


51%
IV Drug Use
28%
Sex with Member of High Risk Group
(IV Drug User, Bisexual Male, Person with Hemophilia, Transfusion recipient with HIV infection, person with HIV infection unspecified risk)
8%
Has HIV Infection, Risk Unspecified
2%
Recipient of Transfusion
11%
Born in Pattern II Country

(Source: Centers for Disease Control. (December 1, 1989) HIV/AIDS Surveillance: Cases reported through November, 1989, Atlanta, GA, U.S. Public Health Service)

than half are caused by maternal involvement in IV drug use (Figure 1-2). While 30 to 60 percent of children born to HIV-infected women will become infected, all will be HIV antibody positive at birth.[1,3] In addition, it can be anticipated that sexually abused children in communities with high HIV seroprevalence are at risk for being infected with HIV.

As heterosexual transmission grows, increasing numbers of adolescents are infected through sexual contact or needle sharing during IV drug use. Crack and cocaine have become major factors associated with the continued spread of HIV, as young addicted adolescents may engage in unsafe sex and prostitution to support their drug habit.[4] Adolescents are more likely than adults to continue their high risk behavior, despite education and knowledge of their HIV-positive status. The reported data from Centers for Disease Control (CDC) relative to AIDS cases in people from 20 to 29 years old, show that large numbers became infected during their adolescent years.[5] Little is known about the actual number of HIV-infected adolescents or their needed care. Increasing numbers of new cases are appearing in persons beyond the limits of the inner city.

Should the current trend of adolescent infection continue unchecked, the long-term outlook for society may be significant. The societal implications of adolescent infection are postulated by the U. S. Surgeon General, Antonia C. Novello, MD, former Deputy Director of the National Institute of Child Health and Human Development of the National Institutes of Health, in an eight-month study of pediatric HIV in the United States:

"The repercussions of HIV infection in adolescents are magnified by the potential

of these sexually active young people to become parents themselves, transmitting the virus to yet another generation. Moreover, Census Bureau statistics show that the cohort of young people currently between 11 and 24 years of age is unusually small to begin with. If AIDS were to make serious inroads in this group, the long-term consequences could be disastrous for the Nation's economy."[6]

Characteristics of HIV in Children/Adolescents

Clinically, there are three major characteristics which distinguish HIV infection in a child from HIV infection in an adult.

First, the clinical signs of HIV illness are present earlier, and its course is more acute in the infant and probably the child, than in the adult.

Second, HIV infection can severely delay the process of growth and development in the child.

Third, in cases of potential perinatal transmission, there is a period of uncertainty when the infant's HIV infection is difficult to document because of the presence of maternal antibodies in the infant's system which may persist through the first 15 months of life. Using antibody tests, it is not possible to determine whether the infant is infected until the mother's antibodies have been eliminated from his system and enough time has passed for the child to produce his own antibodies to HIV. As of this writing, there is hope that new tests to detect the virus or its nucleic acid in infants may allow an earlier determination of which infants are truly infected.

The CDC developed a pediatric-specific classification system, adopted in 1987, which is summarized here:

Classification of Pediatric HIV Infection

P0 Indeterminate Infection

P1 Asymptomatic Infection with:

a. Normal immune function
b. Abnormal immune function
c. Immune function not tested

P2 Symptomatic Infection with:

a. Nonspecific findings
b. Progressive neurologic disease
c. Lymphoid interstitial pneumonitis
d. Secondary infectious disease.
e. Secondary cancer
f. Other diseases possibly due to HIV infection

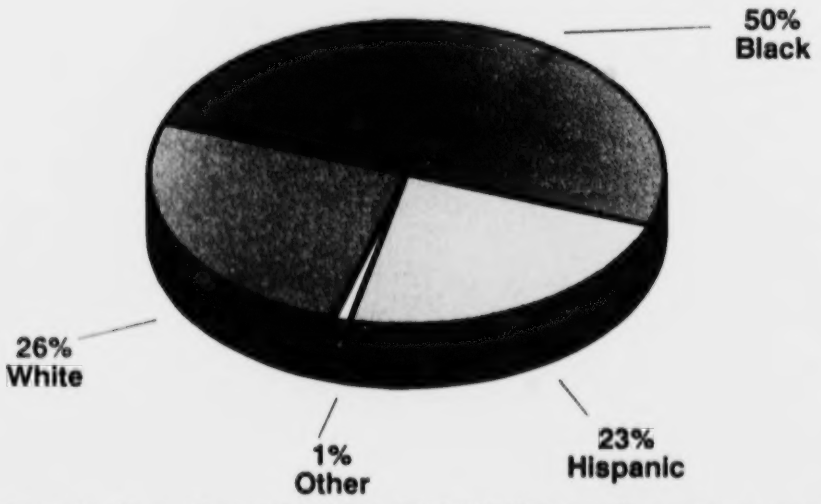
A description of each CDC classification and subcategory is presented in Appendix A, with a listing of related International Classification of Disease (ICD-9) Codes currently in use.

Societal and Demographic Characteristics

There are five specific characteristics which distinguish HIV infection in children and adolescents from adult HIV infection. First, pediatric HIV infection is usually an intergenerational health problem. Eight out of 10 children under the age of 13 with AIDS have an infected parent.[7] Often, two or more persons in the family concurrently face progressive illness and eventual death. Siblings and grandparents frequently provide the day-to-day care and support for a sick child or parent.

Second, care may be provided by sources outside the family. When the family is nuclear and isolated from extended family members, primary day-to-day support must come from sources such as the hospital or community health and service agencies. For example, infants may be left in the care of hospitals or child welfare

Figure 1-3. Cumulative Pediatric HIV/AIDS Cases (<19 y.o.) by Race, September, 1989



(Source: Centers for Disease Control. (October 1, 1989) HIV/AIDS Surveillance: Cases reported through September, 1989, Atlanta, GA, U.S. Public Health Service)

agencies because their mothers are dead, sick, or incapable of caring for them.[8]

A third distinguishing characteristic is that HIV infection affects a disproportionately large number of black and Hispanic children (Figure 1-3). More than half of the AIDS cases in children and adolescents occur in people of color, although they represent less than one quarter of the total population.[9]

Fourth, HIV infection in children occurs inevitably in families with limited resources, already stressed by illness, and unable to provide the care needed by a child with a devastating illness. Dr. Novello's report to the Secretary of Health and Human Services stresses that most children with HIV infection are born into families facing the innumerable problems of poverty, drug abuse, fragmentation, and HIV infection.[10]

And last, recent reports from the Health Care Financing Administration indicate that Medicaid funds pay for approximately 90 percent of the care of children with HIV infection.[11] Many HIV-infected children are cared for in children's and public hospitals where staff, clinic services and resources are already maximally stressed. In locations where the incidence of pediatric HIV infection is highest, such as New York, Miami, Newark, Los Angeles, and Washington, D.C., those stressed facilities now must administer to disproportionate numbers of needy families with overwhelming health and psychosocial problems.

This brief overview of the critical elements endemic to pediatric HIV infection in children provides the basis for developing HIV/AIDS programs for children and adolescents. The reference list following this chapter contains publications relevant to HIV infection in both children and adolescents.

Chapter 2 provides an explanation of the key components of the ten HIV/AIDS programs, as discussed in chapter 4. □

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Chapter Two

Key Components of Pediatric HIV/AIDS Programs

This chapter condenses the list of critical components (Appendix D) into five key components. These form the program structure for care of pediatric HIV infection, which is another unique chronic illness of childhood and adolescence. These key components are common to the programs cited in chapter 4.

AIDS is frequently modeled as an iceberg with the exposed tip representing the CDC-reported cases and the underwater portion representing the HIV-infected population. A new look at HIV infection is called for in light of the chronic illness concept. HIV infection, as a chronic illness, may be viewed as a continuum from infection (which may occur before birth), throughout life, to death. This model of the continuum depicts life as it fluctuates between health and illness (Figure 2-1). Periods of illness (below the axis of the arrow), which recur with HIV disease, grow increasingly more severe. Periods of wellness return, but at levels somewhat lower than during remissions.

The practitioners who shared their recommendations (Appendix F) and expertise

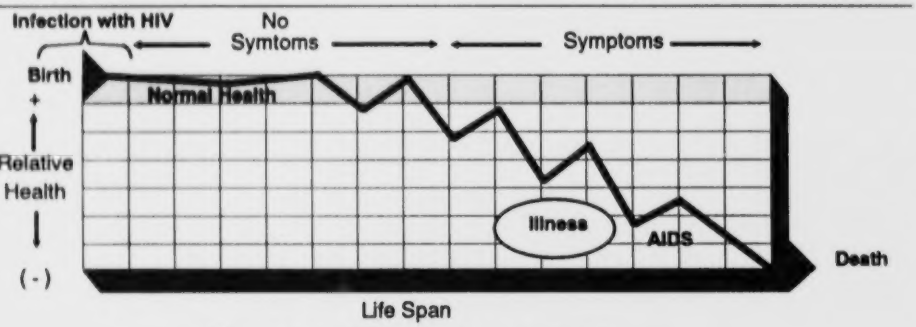

Figure 2-1. HIV Infection...a Continuum

for this *Sourcebook* agreed that children infected with HIV need care from the earliest point, when the possibility of infection is suspected. Care may be needed for several years—from HIV testing, through confirmation of HIV infection; latency; times of wellness when growth and development can occur; and through the stages of debilitating illness, death, and bereavement.

KEY COMPONENT 1

HIV is a chronic illness which requires pediatric primary health care services.

HIV/AIDS is not an epidemic of childhood illness beginning and ending in a hospital as some thought. It is a chronic infection requiring long-term planning for a young life.

An illness that lasts three months or more, or requires at least one month of hospitalization, is classed as a chronic illness and generates family stress with needs for special health care services.[1] Children with chronic illness have an ongoing need for special psychosocial and health care services. Obtaining and maintaining these services require inordinate amounts of time, energy, and resources of the family, stressing its capability to cope with the demands.

Administering to children with HIV chronic illness requires the long-term involvement of both the family and the health care team in the following areas:

- Halting or slowing the disease process and its sequelae
- Continuing to live as normal a life as possible
- Promoting growth and development
- Assisting children to maximize their potential in all possible areas
- Anticipating and minimizing the social and behavioral consequences of the pathological condition[2]
- Providing preventive education that may help curb the spread of AIDS
- Supporting the family grieving over a child's illness and death

Along with a multitude of services, it is necessary that the child maintain a contact point within the HIV program, such as a specific health care provider who has the respect and attachment of the child and family (See Key Component 4—Case Management, page 11). The primary health care provider sees the child in the periods of relative wellness, to provide guidance and counsel, to give immunizations, and to help him/her grow and develop as much as possible.

EXAMPLE: The physicians and pediatric nurse practitioners (PNP) provide not only specialty care in their HIV clinic sessions, but also ongoing primary health care throughout the week at these hospitals:

- Children's Memorial Hospital, Chicago (chapter 4, page 53)
- Childrens Hospital of Los Angeles (chapter 4, p. 54)

Routine childhood immunizations are given, parents receive anticipatory guidance on the growth and development expected at particular ages and stages, parents' questions are discussed, minor illnesses are identified and treated, referrals are made and monitored, health concerns at the child's school are resolved, and when the child is hospitalized, the primary health care provider remains active in caregiving.

KEY COMPONENT 2

Approach must be child-centered and family-focused.

The variety of activities needed to provide care in so many areas—physical, mental, psychosocial and spiritual—tends to disrupt life as the family once knew it. A pediatric HIV program should be designed to accommodate these needs of the children and their families. Services should be streamlined and centralized to ease the complexity of hospital visits, such as reducing the number of departments to which a patient must report and minimizing the amount of time spent in the hospital.

For example, parents and children should not have to precede their clinic appointment with a stop at the admitting office to register, then to the accounting department to settle the bill, then to the laboratory to have specimens taken, then wait for long periods of time before being seen by the care team. It is recommended that all four activities occur at the same location, and in the same time period of the clinic visit.

EXAMPLE: The Maternal Infant Care for HIV Program in Detroit at Children's Hospital of Michigan (MICH) is a working model of this key component. Children and their mothers receive their care simultaneously in a facility used by both pediatric and adult health care providers. The clinical ambulatory services are located between the Children's Hospital and the Women's Hospital on the campus of the Detroit Medical Center. It is there, physically adjacent to the Children's Hospital, where children infected with HIV and their mothers are cared for by the interdisciplinary team of health and social service professionals. See chapter 4, page 50.

Staff should be trained to understand and be able to respond to families' anxieties and grief. Caregivers in established programs give advice such as:

- Hospital staff must model caring—give hugs to children daily.
- Services offered must be non-judgmental, friendly, competent.
- Since pediatric AIDS is a family illness, plan to provide combined care to mother and child together.
- Balance care and treatment with research.
- Do not allow children to die alone.

KEY COMPONENT 3

Care is interdisciplinary, coordinated and collaborative.

Interdisciplinary

Because the needs of HIV-infected children and adolescents are complex, a broad range of services are required to meet their needs. A full team of professionals and volunteers must work together to support the family. Providers of care for those needs include: child life, development, education, medicine, mental health, nursing, nutrition, social work, pastoral counsellors, occupational/physical/speech therapies, and an array of medical specialists to consult on special conditions related to HIV infection.

EXAMPLE: Jackson Memorial Hospital's Pediatric AIDS Health Care Demonstration Project in Miami, Florida is one of the projects that displays the full spectrum of primary health care services for HIV-infected children. The interdisciplinary nature of this program is modeled by

its leaders: the nurse and social worker co-directors. See detailed description of the program and its services in chapter 4, page 49.

Coordination and Collaboration

The interdisciplinary teams must communicate with one another and work in a closely coordinated manner. The interdisciplinary health care teams collaborate on individual child care plans under the leadership of a case coordinator.

Team members should be carefully chosen not only on the basis of their clinical/experiential expertise, but also on their willingness and ability to communicate and function as part of a team. One HIV program director stressed that the main prerequisite for any team member should be *willingness to serve* HIV-infected children and their families. However, that willingness must be coupled with the willingness to communicate while serving.

Collaboration to provide care for a child is accomplished only when providers meet regularly and work out a common plan that details the goals for that child. The pediatric AIDS programs that describe themselves as "successful" all hold regular team meetings for updating, problem solving, planning and coordinating of patient care and support services.

The Special Infectious Disease Clinic at Children's Memorial Hospital in Chicago, the Adolescent AIDS Program team at Montefiore Medical Center in New York City, and the Children's Hospital AIDS Program, New Jersey demonstrate this third key component of a model HIV program: interdisciplinary, coordinated, collaborative care.

The following paragraphs contain brief descriptions of how those institutions are employing this technique.

EXAMPLES: In Chicago, the Special Infectious Disease Clinic team at Children's Memorial Hospital meets four days after the weekly clinic session for its "post-clinic conference." Disciplines represented in these meetings include medicine, nursing (inpatient, ambulatory and home care), social work, child life, mental health, and speech therapy. The PNP who coordinates services for HIV-positive children present case summaries, then lead the conference in planning and problem solving. Following the conference, the main points of discussion and the outcomes are documented in each patient chart, thereby providing an ongoing record of collaborative actions. See chapter 4, page 52.

In New York City at Montefiore Medical Center, the Adolescent AIDS Program team coordinates and collaborates on Friday mornings, then holds its clinic the following Tuesday. See detailed description of attendees and discussions in chapter 4, page 36.

The team at the Children's Hospital AIDS Program in Newark, New Jersey meets weekly for case review and planning following its clinic session each Friday. The disciplines represented at those meetings include medicine, nursing, social work, nutrition, home care, and program administration. Initially, a physician or PNP presents a brief update of each patient for consideration and discussion. Current therapies and their effects are reviewed, and the team makes decisions regarding the continued therapeutic regimen in each discipline. Problems occurring subsequent to the last review are analyzed, and solutions sought. When proposed solutions fail, new approaches are planned. The team member closest to the patient and the problem usually benefits from the ideas of the other team members who can look at the situation with greater perspective and recommend

alternatives more clearly. See chapter 4, page 41.

The majority of programs hold weekly interdisciplinary meetings to collaborate on the care of patients seen in clinical sessions, and to resolve emerging issues during that week. Between weekly meetings, ongoing inter- and intra-agency collaboration is facilitated on a day-to-day basis by the case management system.

KEY COMPONENT 4

Each child with HIV infection requires a case manager.

Case management, as a tool, is effective in facilitating appropriate medical treatment and providing coordination for a comprehensive plan of care. Case management is a process in which one team member is responsible for planning, locating, coordinating and monitoring a group of services designed to meet the individual needs of patients, while helping children and their families remain as independent as possible for as long as possible. [3,4,5]

The case manager keeps abreast of the total management plan for the child, and facilitates the implementation of that plan. To accomplish this, the manager keeps in close touch with both the child and family, and knows the child's current health status and level of coping with the infection.

For example, through ongoing communication with all the disciplines and services scheduled for the child, the case manager coordinates with home care services to insure that visits are maintained, and that the family has obtained the needed supplies and equipment for home use. The case manager assists the child and family in the accomplishment of various tasks, such as obtaining entitlements, and scheduling ambulatory service visits when laboratory work, medical treatment, financial counseling, or social counseling are required. When the child is sick and needs hospitalization, or when transportation, rescheduling, or referral is necessary, it is the case manager who makes the arrangements and ensures that the required care is provided.

EXAMPLE: In the Pediatric AIDS Health Care Demonstration Project at Jackson Memorial Hospital, Miami, the case managers reflect the socio-cultural mix of the community. Patients receive racially sensitive, culturally appropriate case management for their care in the program. See chapter 4, page 48.

Information on a computer-based case management system is presented in the Los Angeles Pediatric AIDS Network model in action in chapter 4, page 54.

The fifth, and final key component essential to establishing a viable HIV/AIDS program for children and adolescents relates to the community in which it is, or will be, located.

KEY COMPONENT 5

HIV care programs require community support.

Those experienced in this field have recommended repeatedly that gaining community support is prerequisite to starting a program. This single factor is possibly one of the most important in predicting the success of a new HIV program in the community. For instance, the Children's Hospital AIDS Program of New Jersey recommends that you develop an "AIDS Information Committee"and develop guidelines for media relations. Harlem Hospital suggests that you take a proactive stance and turn media attention to your favor by stressing the positive aspects of your AIDS program. And Childrens Hospital of Los Angeles advises that you present your hospital's development of an AIDS program as just

one more way your organization is an advocate for children in your community.

Care for these children should not be taking place in a vacuum—the community must be educated; school and government leaders must be approached for support; and proactive programs must be initiated. With the community and its political leaders in support of an HIV program for children, success is certainly assured. Without it, many barriers will confront the program planners and promoters.

The five components described in this chapter should be used as the foundation of any program that is to care for children with HIV/AIDS. In summary, the keys are:

- HIV is a chronic illness and requires pediatric primary health care services.
- Approach must be child-centered and family-focused.
- Care is interdisciplinary, coordinated and collaborative.
- Each child with HIV infection requires a case manager.
- HIV care programs require community support.

Chapter 3 outlines the steps necessary to assess, plan, and implement your program. □

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Chapter Three

Mobilizing For Program Organization

Keeping in mind the overview of pediatric HIV infection in chapter 1 and the key components of care in chapter 2, we turn our attention now to mobilizing for program organization.

Many hospitals already have successfully established programs to care for their HIV/AIDS patients. For those hospitals, this chapter may give insights into improving programs, or may help to justify a reorganization or expansion of program services.

For those hospitals just beginning to identify HIV/AIDS in their communities, this chapter is a step-by-step guide to establishing a program of care through assessment, planning, implementation and evaluation. Detailed guidance is offered for the first three steps, and general instruction for the fourth step.

Assessment

A critical first step in bringing about change is assessing the situation in need of change. It is crucial that all relevant segments of the hospital be included in assessing the need and planning the change, because all relevant segments will be affected by the complex needs that HIV-infected children and adolescents bring to the hospital.

Initially there may be a core group which is educated about the growing presence of HIV/AIDS in children and therefore is more sensitive to the urgency for assessing the hospital and its community's anticipated needs and ability to respond. If a core group does not already exist, one should be developed.

Early in the assessment process, this core group must seek the support and participation of hospital leadership at all levels, including executive management,

medical and nursing staff, faculty, social work and environmental services.

The assessment process can begin once you have identified the HIV/AIDS issue; formed an interdisciplinary group which is committed to discovering the parameters of pediatric HIV infection in your hospital and community; created an institutional awareness; and secured support for this activity.

Six Steps in the Assessment Process

1. Assess the numbers of HIV/AIDS patients receiving care.

2. Share the findings with management and seek agreement on the need for a broader-based community assessment in order to determine the potential impact of HIV/AIDS on hospital services and staff.

3. Perform a community assessment using the guide in Appendix B.

4. Review hospital and community findings with management to obtain consensus on the fact that there is a problem with HIV/AIDS infection in children and adolescents "right here at home," and that something should be done about it.

5. Identify what impact a pediatric HIV/AIDS program would have on the hospital, what constraints would prevent the establishment of a program, and what emerging issues must be addressed.

6. Present the findings from your assessment to hospital executive management staff, and propose that a planning committee be convened to recommend courses of action based upon the assessment results, and establish plans for implementing a program.

STEP 1.

Preliminary Assessment of Patients

You will need to gather information on the numbers of children with AIDS or HIV-related illness admitted to your hospital and seen in your outpatient and emergency departments. The information you need to gather includes:

- How many cases of AIDS or non-AIDS-related HIV infection have been seen yearly in your facility since the early 1980s?
- What is the monthly total seen over the past 12 months?
- What is the trend?
- How many discharge diagnoses can be linked to an HIV cause?

The one factor that may complicate your documentation of figures is the fact that many patients may have been seen for health problems related to HIV but not identified as HIV-related. The following diagnoses or admitting problems may indicate the presence of HIV infection:

- Delayed development
- Loss of neurological function
- Frequent infections
- Enlarged lymph nodes
- Failure to thrive or wasting
- Recurrent pneumonia
- Oral thrush, prolonged, recurrent
- Enlarged liver and/or spleen

- Salivary gland enlargement
- Chronic diarrhea
- Recurrent bacterial infections
- Opportunistic infections (Pneumocystis carinii pneumonia, cytomegalovirus infection, cryptosporidiosis, etc.)
- Hematologic disorders
- Hepatitis
- Nephropathy
- Cardiopathy, vasculitis
- Skin disorders (herpes, herpes zoster, warts, eczema)
- Lymphoma, non-Hodgkin, B-cell
- Lymphoma, primary, brain[1,2]

To determine whether any of the patients for whom these conditions are reported are HIV-positive or infected, you should review the patient's medical records, histories and laboratory findings. Your medical record staff may review the HIV related International Classification of Diseases (ICD-9) codes assigned to patients at discharge (Appendix A), to identify former inpatients. In addition you may collaborate with your laboratory to obtain a confidential list of HIV-positive patients.

STEP 2.

Share Findings With Management

It is important to establish that an increase in the number of children with HIV infection will affect the entire institution, not just a particular provider, department, or discipline. Using this framework, share your findings to date with management. This should provide an impetus to explore institutional approaches to the problem and to determine mechanisms for informing the community of this emerging need within the hospital's service area.

Executive management can begin building institutional support for confronting and dealing with the newly emerging issue of HIV infection. Seek to engage the services of your hospital planning department to assist in the methodical collection of data which reveal the extent of the HIV prevalence in your institution and community. Those experts will have the tools and strategies to facilitate both assessment and planning.

Without a planning department, you may select someone on your staff, engage a consultant, or use a willing, knowledgeable volunteer to gather data according to the assessment guide in Appendix B.

STEP 3.

Community Assessment

A. IDENTIFY THE EXTENT OF THE ISSUE

Using the format in the community assessment guide (Appendix B), document the number of current cases of children with AIDS, and examine the evidence of HIV infection in the maternal-child-adolescent population. Compare those figures with national statistics, and try to determine what the trend may be in your community. Gather information from your city, county and state health departments and compare the figures with those reported nationally by the CDC in the HIV/AIDS Monthly Surveillance Report published at the beginning of each month.

The official local or national figures may well be lower than those in your locale because the national figures are based on a

"surveillance" definition of AIDS, which includes fully developed clinical cases, not HIV infection alone. For instance, the Children's Hospital of New Jersey in Newark was treating three times as many HIV-infected patients as CDC was reporting for the state.

Project future needs. Analyze the number of AIDS cases reported in your state's Standard Metropolitan Statistical Areas (SMSA) and your state as a whole, since the start of the epidemic in the early 1980s. Scrutinize the figures from newborn screening programs, sexually transmitted disease clinic records, and the health records of military recruits and job corps applicants. Look at the demographic characteristics of the groups of persons reported with AIDS. How does the proportion of affected children, adolescents and adults in your state compare to those proportions in the U.S. as a whole? Is there a large number in the 20- to 29-year-old age category who may have become infected as adolescents? If the numbers in this category are large, might you expect more newborns with HIV infection? Calculate that for every reported AIDS case, there are from 2 to 10 more unidentified HIV-infected individuals in the community who will eventually become ill.[3]

Your figures will help you make the decision as to whether you need to move quickly to accommodate a potentially rapid growth in the population of pediatric HIV/AIDS patients, or whether you have some time to plan.

Categorize cases by age. Not only do you need to document the numbers of cases of AIDS/HIV in infants, children, and adolescents, but you need to categorize these cases into types. The nature of the program you will develop depends on the population that needs to be served. Listed below are three categories, which are established by age group:

(1) Infants and toddlers: HIV-positive infants undoubtedly have an HIV-infected parent or parents. These infants require care and treatment by pediatric specialists. The whole family will need the attention of the entire spectrum of health and social services as the HIV infection takes its toll on parents' ability to provide care and nurturing for the infected child.

If the number of cases of infants born HIV-positive has increased over the last few years in your community, you might plan to provide care for these infants as well as to begin a major community program of preventive education among adolescents and women of childbearing age.

(2) Pre- and school-age group: First, identify the modes of transmission. Incidence of blood-related transmission will level off and eventually decrease due to the screening procedures instituted in 1985 on blood and blood donors. HIV should no longer be transmitted in this manner. If the majority of the cases in your area fall into this category, your need for establishing a program of care may not grow. However, if sexual abuse of children is reported frequently in your community and HIV is present, you may need to plan for an increase of pediatric HIV/AIDS cases.

(3) Adolescents: Many adolescents are sexually active and thus could acquire HIV infection during sexual relations, and subsequently become the parent of an HIV-positive child. A growing AIDS incidence in this population in your community will require planning for counseling and testing services, preventive education, genetic counseling, and care and treatment facilities for both adolescents and infants infected with HIV.

B. IDENTIFY COMMUNITY REOURCES

Your next task in identifying the problem in the community is to find out what resources currently exist in your community that address the needs of HIV-infected children and their families.

Health Care Facilities. Determine the types of health care facilities that are providing care or could accommodate children infected with HIV at the different stages of their illness, such as the following: a children's hospital; a general hospital with a pediatric unit; a long-term care facility for children; a transitional facility to care for parentless children; and a hospice to care for dying children. Also, determine whether they have ever had AIDS patients and whether the medical staff can gain access to the AIDS Clinical Trials Groups (ACTG) for medications to treat the condition.[4] When assessing these facilities, determine the occupancy rate and whether they could accept more patients.

Community-based centers. Look at the number of community health centers accessible to your population that provide episodic and primary health care. Determine if they can handle the hematologic and immunologic monitoring so important in treating HIV/AIDS children. Are they providing the outpatient-based treatment needed by HIV-infected children with progressively increasing episodes of opportunistic infections, or referring them elsewhere?

In addition, determine if the hospital and community agency boards are currently informed about the breadth and depth of the HIV problem in their institution and community.

You may survey these groups by telephone, talk with your state's AIDS Coordinator (Appendix C) who may have a sense of the general level of knowledge in these groups; talk with your administrators to poll your board of trustees to see what their individual networks tell them; or commission one or two of your more active, informed, mature and sophisticated volunteers to conduct interviews to collect this data. Ask your planning department to offer strategies for this type of data collection.

Care providers. HIV/AIDS patients need a greater variety of care providers and more of their time than do children with routine childhood illnesses. You need to determine if your community has a sufficient number of care providers for new cases of HIV infection among infants, children and adolescents. The following types of care providers are needed:

- Social workers
- Pediatricians
- Pediatric nurse practitioners
- Internists
- Family practitioners
- Other primary health care providers

How many of these people are located nearby and are both willing and prepared to provide care? While being sensitive to confidentiality issues, find out if they are seeing children and families with HIV infection. Are they linked to a referral network or system where they have hospital privileges? How established is the hospital's tie-in to community care givers? Have you had experience with other providers as they worked with children with other conditions? When looking at the availability of care providers, determine if they are accessible to patients. Do financial, eligibility,

policy, or bureaucratic barriers exist which hinder access?

Funding. What is the economic situation in your area? What reimbursement structures exist to meet health care costs for children infected with HIV? You will need to assess the local funding sources for care: third party payers, Medicaid waivers for home based care, Medicare benefits under SSI, crippled children's services, etc.

C. ASSESS COMMUNITY ISSUES

Public Relations. Because of public education campaigns by the Surgeon General, society on the whole is better informed about the realities of HIV/AIDS. Yet, the potential for AIDS hysteria to grip a community and stimulate antisocial behavior remains a threat. For example, The New York Times reported that a group of citizens set fire to a house in New York City in 1987 that was designated as a group home for boarder patients.[5]

You will need to assess the level of understanding and tolerance for HIV/AIDS that exists in your community. This assessment will provide a gauge for predicting what the community reaction might be to the news that an HIV/AIDS program is being established at your hospital. Further, it will identify the amount and nature of community outreach and public education that will need to be initiated while you are planning the program, and during implementation and operation of your established program.

Enlist the aid of your public relations department. Find out if it has the capability to handle media questions about HIV/AIDS. Also, ask if it has a sense of how the community would react to the establishment of an AIDS program. Find out if a trustee or board member who may be politically influential could serve as a liaison with the political and business community, the media, etc.

Contact your local community organizations and inquire about ongoing programs in which your hospital may participate; what resources they know of for public education; and what legal issues are related to children with HIV. You may find a community leader who will act as a spokesperson for the cause of facing the HIV/AIDS issues in your community, and in support of organizing a pediatric program. Community leaders and organizations to contact may include:

- School representatives and parent-teacher organizations
- Key community leaders and politicians
- Churches and synagogues
- Employers of large numbers of people in your community
- State AIDS coordinators
- Health care provider groups and hospices
- Local ethnic organizations
- League of Women Voters and Junior League
- Community action agencies

Political issues. Assess the political climate and consider its effect on a proposed HIV/AIDS program. Review past editorials and newspaper articles about the subject and talk to key community leaders and politicians. How do your local politicians stand on the many issues of community interest regarding HIV/AIDS?

You also need to enter the legislative process in your state as an advocate for funding of programs for children with HIV/AIDS. Be aware of what kinds of bills are being considered that would regulate policy and provide funding and other resources for AIDS programs. Find out which legislators are involved and encourage their efforts. Be prepared to act as a resource to legislators who are unsure of the issues surrounding AIDS funding. Keep in touch with your state AIDS coordinator (see Appendix C).

D. ANALYZING COMMUNITY ASSESSMENT FINDINGS

Analyze the findings from your community assessment, combine those results with the hospital assessment, and consolidate your case definition of the magnitude or the potential magnitude of the pediatric HIV/AIDS incidence in your community.

Prepare for a second meeting with your hospital management. At this meeting, you need to bring:

1. Numbers of HIV/AIDS patients treated at your hospital during the past 12 months.

2. Numbers of HIV/AIDS patients in the hospital's catchment area reported by both local sources and CDC (infants, school age, adolescents).

3. Trends in numbers during the past 36 months.

4. Health services available in the community (as in community assessment guide outline), and the unmet health care needs requiring hospital attention.

5. The relationship and strength of association with community providers (how much work will be needed to ensure community-based care).

6. Community attitudes/mindset.

7. Political issues, such as voting records and related legislation.

STEP 4.

Review Hospital And Community Findings With Management

Your anticipated outcome from this meeting is to obtain consensus on the status of HIV infection in children and adolescents in your community and the commitment that something should be done about it. At this review, you will need to reach a consensus about whether you need to start a pediatric HIV/AIDS program in your facility, or link with an existing program in the vicinity. Hopefully your discussion will prompt management to plan a critical review of the internal and external reactions to the announcement of the development of an AIDS program. You will be able to assist in this review by exploring the impact on the organization, as described in Step 5.

STEP 5.

Impact On The Organization

Change or reorganization will accompany your decision to establish a new HIV/AIDS program, and you must anticipate how these changes will affect the organization. In addition, you need to identify obstacles to these changes and plan how you will respond to them. The proposed changes may affect several areas of the hospital: structure/organization; staffing; support services; finances and funding; and image. It is important to look critically at these significant areas and anticipate the questions you will need to address in your planning for the new program.

STRUCTURE/ORGANIZATION. Look at the existing structure of the organization and determine where an HIV/AIDS

program will fit. A new HIV/AIDS program may easily evolve from an existing clinical service. Otherwise, you may have to consider altering the physical space and assessing if new equipment and supplies are needed. If the organizational structure must be changed to accommodate a new department, new positions and lines of authority may have to be created. For instance, are changes required to provide primary care (that includes counseling and testing) in your ambulatory services?

At this point, you also need to determine if starting a program will be consistent with the hospital's mission, goals and objectives. Is the mission and purpose of your hospital compatible with the key components recommended by those experienced in pediatric AIDS care? (Refer to chapter 2 and Appendix D — Critical Program Components.) For instance, will many changes have to be made to incorporate child-centered and family-focused policies and procedures?

Look at the hospital's present policies and procedures to determine if they address the issues listed below. Committees will need to consider these issues. You may already have in place a committee structure that is able to address each concern appropriately. You also might want to talk with peers in the cited programs to compare your policies with those experienced in this area. National norms have been set by the Occupational Safety and Health Act and the CDC. How does your hospital meet these norms? Consider these topics:

- Infection control (including universal precautions)
- Contaminated waste disposal
- Employee health services for exposure to HIV at work
- Informed consent for testing procedures
- Privacy rights and anti-discrimination

EMERGING ISSUES. You will need to be informed on the following emerging issues and be prepared to address questions from your management, trustees, funders and the community to allay fears and support your position.

1. *Informed consent*: Assess your state laws and your hospital's written polices and procedures. Do the hospital policies consider:

- Who gives informed consent for a child/adolescent?
- Who in the organization is authorized to elicit informed consent?
- Is consent for testing needed when a child has a history of possible exposure to HIV, such as sexual abuse or having a drug-abusing family member?

2. *Testing:*

- Has your hospital begun developing a testing policy?
- Have you considered a testing policy related to both patients and employees?
- Have union groups been consulted about employee testing?

3. *Confidentiality:* Determine if you need to provide hospital employees with educational sessions on maintaining confidentiality about patients' and their families' HIV status.

- Should records be locked and made accessible only to key staff members?

- How does your institution protect the patient's confidentiality when professionals from other agencies, such as AFDC, Medicaid, WIC, and Child Protective Services are involved?

- How do you strengthen and maintain the confidentiality of patient records?[6]

For legal assistance with HIV-related matters, consult your hospital counsel; the National Pediatric HIV Resource Center; or the National Health Law Program in the Resource List in Appendix E.

STAFFING. Determine if you have all the disciplines on your staff to form a team. If not, decide what new positions need to be created. See Appendix D for recommended staffing.

Next, evaluate the knowledge of the hospital staff about HIV/AIDS and try to determine if they realize the complexities of care for children with HIV infection. Look at the attitude of the hospital and medical staff toward accepting a new program that may require them to expand their repertoire of caring skills.

Another factor to consider about your staff is whether it is capable of responding quietly and confidentially to the sometimes traumatic and emotional occurrences that may accompany the establishment of a pediatric HIV/AIDS program. Will you need to offer seminars or support groups to deal with such issues? The Hemophilia Comprehensive Care Center at the Childrens Hospital of Los Angeles began a staff support group to discuss the psychological impact that HIV has on patients, family and staff. Part of their AIDS budget includes the salary for a mental health professional who leads these discussions aimed at reducing stress.

To determine whether the staff is educated and trained in the continuum of care and treatment needed by children with HIV infection, talk with department heads and gain their perspective on the following questions:

- Will in-service education need to be a few hours or more than a week long?

- Are the direct caregivers familiar enough with current pediatric HIV/AIDS therapy to begin work immediately?

- Are the aides, orderlies, assistants, technicians and transporters interested and willing to learn how to do their work appropriately and safely with HIV-infected children?

- Who will prepare the curriculum for the staff?

- Do the following support services staff need education: admitting, volunteer department, laboratory, X-ray, dietary and housekeeping?

- What time and education allowances will need to be planned?

SUPPORT SERVICES. Determine if local laboratories can handle the specific tests (immunoglobulin studies, absolute T-helper cell counts, T-cell ratios, arterial blood gases, hepatotoxicity monitors, etc.) and provide the required biologicals needed for treatment of children with HIV infection. Are there medical supply firms in your community which lease equipment for

home use, such as oxygen tanks, infusion pumps and hospital beds?

FINANCING/FUNDING. It is important to project the anticipated costs of the program and identify where your finances will come from. Ask your finance department to assist you in projecting the operating costs for an HIV program, and your development department for assistance in raising money. Discuss with your development department or grants administrator the possibility of initiating a fund raising campaign (which could be publicly sensitive) or exploring available grants. The booklet, *AIDS Funding,* may prove to be a helpful resource.[7]

Also look at the timing of the program in terms of finances: Is this a good time in the economic life of the organization to start a new program, or are you in the midst of a building campaign, is the census drastically low, or has state or municipal funding been severely cut?

Consider the following direct and indirect costs that will be incurred in this complex type of care: supplies and equipment, special disposal services for infectious waste, new employee health services, additional blood factor products, inadequate health insurance and Medicaid reimbursement, additional staff recruitment, education and support to prevent burnout and rapid turnover, increased staff time spent on community education, increased social services and outreach activities.

Explore the economic impact on your organization that will result from providing care to a group of children largely financed by Medicaid. One established pediatric AIDS program at Children's Hospital of New Jersey, reported in its 1987 annual report that unreimbursed costs for Medicaid-financed pediatric AIDS patients increased nearly three-fold in two years. They attribute the annual loss of $77,000 for the care of HIV/AIDS patients as the "Cost of Compassion."[8]

IMAGE. There is a possibility that your image in the community will change when you are known for providing care to HIV/AIDS children. You need to determine if the hospital wants to be vocal or discreet about the HIV/AIDS program. This will determine the public relations strategy.

The community assessment will help you in determining how the community may react to the establishment of a new HIV/AIDS program for children. In either case, the hospital should be proactive rather than reactive when it comes to community response. Is your public relations department prepared and willing to face the media with answers to their probing questions? If not, meet with the staff to find out what assistance it needs to mobilize and deal with the work of informing, educating and integrating the hospital's new program into the community.

STEP 6.

Present Analyzed Findings to Hospital Management and Establish Planning Committee

PRESENT TO MANAGEMENT. You have now completed a thorough assessment of the situation in your community and institution regarding the current incidence of HIV/AIDS, projected trends and needs, available resources and impact on the organization.

List the constraints you think may prevent you from providing the services that children with HIV infection need in your community. These issues may include insufficient finances; inadequate facilities; skeptical local attitude toward AIDS; blatant prejudice or discrimination; lack of interest by leaders who think that this is not

a large enough problem to worry about or plan for; uninformed leaders; or any of the other issues discussed throughout this assessment section.

Review with the administration your hospital and community assessment, your analysis of the impact on the organization and proposed recommendations.

ESTABLISH PLANNING COMMITTEE. Once the hospital administration has made a commitment to action, and you have decided your course of action, establish a planning committee. The planning committee is the core group that oversees the development and implementation of the program and sets the tone of the overall institutional plan, and for the planning that will follow in each department. The framework will be established as the committee defines the institution's mission, purpose, goals and objectives for the HIV/AIDS program.

The committee should be comprised of representatives from the involved disciplines and departments concerned with this new program, including administration (planning, public relations finance, and support services), nursing, social work, and medicine.

Planning

Your assessment has documented a need for a program to serve HIV-positive children; you have secured the support of the management, and you have appointed a planning committee comprised of representatives from key disciplines and departments. You are now ready to map out a course to implement your pediatric HIV/AIDS program.

Each of the following five sections is assigned to key players in the planning process. The first section, written for the planning committee, is the most comprehensive and detailed and should be used as a model. Subsequent sections are shorter and only address issues specific to that discipline.

Each section is divided into planning phases in the order in which they should occur. They are as follows:

Hospital Mission Statement: What do we want to do?

Purpose: Why do we want to do it?

Goals: What outcomes do we want to achieve?

Objectives, Task Identification, Timeline: How and when do we want to do it?

Evaluation: Did we do it?

Although working on separate tasks, the planning efforts of each committee member are essential to the totality of the program. Caregivers, administrators and planners need to communicate with each other often to coordinate their efforts. Most of this communication will probably take place within the planning committee which is made up of representatives from each discipline. The following four groups will be working together on the planning committee to plan and implement the new HIV/AIDS program:

- Administration
- Physicians
- Nurses
- Social workers

I. PLANNING COMMITTEE

The planning committee is responsible for drawing up a comprehensive plan that will be used to guide planning and imple-

mentation of the HIV/AIDS program. The plan should be incorporated into an organized review of the basics of the HIV program purpose, goals and objectives; should be submitted to the hospital leadership and the board of trustees for approval; and then distributed to departments. Figure 3-1 provides a useful format for documenting the "what, who, and when" of your plan.

It is most helpful if planners meet with department heads and their assistants to discuss the details for which they are responsible, and to clarify any questions.

The committee's first task is to prepare a proposal that clearly describes the purpose, goals and objectives for the program. The proposal will establish the overall framework from which each discipline will derive its own directives. It should be approved by the hospital leadership early in the planning process.

Included in the proposal should be three essential elements:

1. A budget for the overall project and for each department.

2. A realistic projection of when the program can begin operation. This date should reflect the urgency found in your assessment. If you have an increasing number of children with HIV infection, you may need to plan your program implementation in phases.

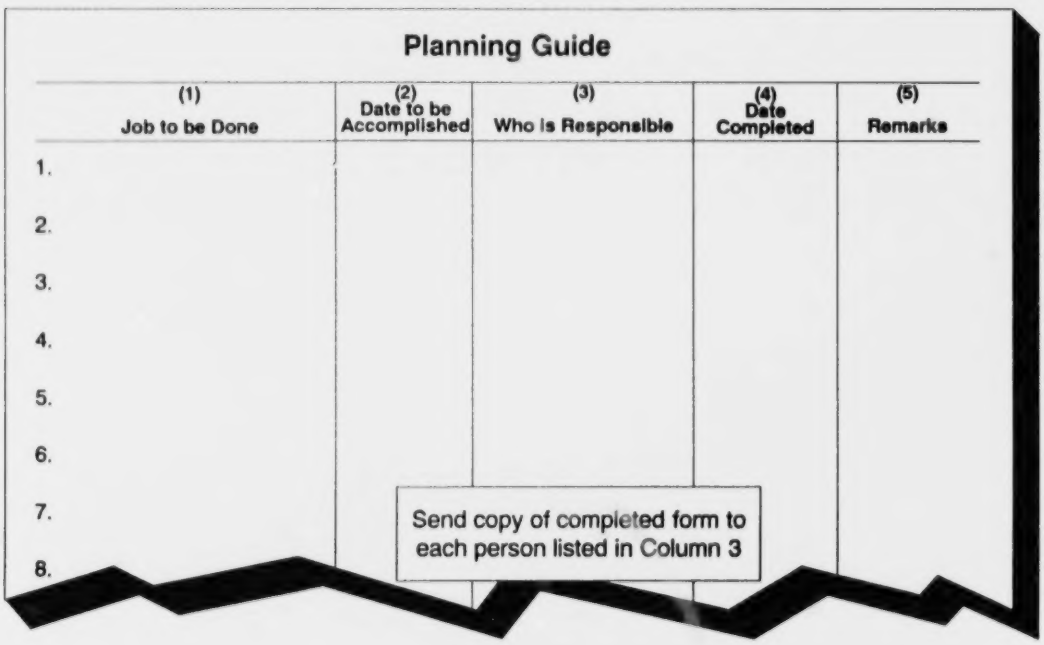

Figure 3-1. Planning Guide

3. Location of the program addressing such issues as: adequacy of existing hospital space; acquiring or building additional space, if on-site; renting, buying or building a location off-site.

Mission Statement

Write a concise, one paragraph statement of the program's intent describing what you want to do. Make it consistent with the mission statement of the hospital.

EXAMPLE: *Anytown Children's Hospital, in keeping with its proactive mission to serve the health care needs of the infants, children and adolescents in its community, will provide preventive, diagnostic, therapeutic, habilitative services and support to its pediatric community in need of care for the chronic illness resulting from HIV infection.*

Purpose

Define the program's purpose. State why you want to address this new pediatric illness. Use the material you gathered during the assessment process to justify the need for the program.

EXAMPLE: *In our community, there are no providers who can meet the multifaceted requirements of care needed for HIV-infected children and adolescents in a "one stop" manner. Anytown Children's Hospital's HIV program is designed to provide comprehensive, coordinated, child-centered, family-focused care delivered by an interdisciplinary team of health and social service professionals.*

Goals

Establish the goals which you would like this program to achieve and include the population that you want to serve. The goals should be measurable and attainable. Sample goals follow:

- To offer counseling, testing and referral to children 13 to 19 years of age in the hospital's catchment area
- To include components in our program to meet the physical, mental, and spiritual needs of HIV-infected children and their families
- To offer health care services for every phase of the continuum of HIV infection from prevention, primary, secondary and tertiary care, through death

Objectives

Conceptualize how you will achieve your goals through broad-based statements.

EXAMPLE: *To begin the HIV/AIDS program within three months we will need to:*

1. Write the proposal and submit it to the board of directors and trustees for approval.

2. Rally hospital employee support.

3. Orient the public relations department staff about the new program.

4. Inform the general community and gain its support through public relations campaigns.

5. Raise funds.

6. Begin internal and external educational campaign.

7. Procure equipment, supplies, personnel.

8. Orient staff.

9. Begin caring for patients.

10. Add material and personnel as patient numbers increase.

Task Identification

At this point, you will identify and list tasks in the priority in which they will be accomplished. Assign which discipline or department will be responsible for the task. These tasks are based upon your objectives, but are much more detailed.

EXAMPLE: *Objective: Write the proposal.*

1. The finance representative draws up a proposed budget after consulting with affected departments, brings to next meeting for committee input, and completes budget based upon committee recommendations.

2. Administration representative draws up a projection of who the program will involve and when the program will begin, submits it to the committee and finalizes it based upon recommendations.

3. Planning department identifies the location of the program, submits it to the committee and finalizes it based upon recommendations.

4. Public relations representative puts together and finalizes the proposal.

5. The committee submits the proposal to the board in two months.

Timeline

Estimate the time it will take to accomplish each task on your list, and identify when you need to start each task. Use the planning guide to help you with your timeline (see Figure 3-1, page 24) and monitor the overall progress of the project through completion.

EXAMPLE: *In two weeks: Committee reviews portions of the proposal submitted by various committee members.*

In four weeks: Committee members complete proposal sections based upon committee comments; turn them over to the administration representative to consolidate and complete.

In six weeks: Administration representative completes proposal, and brings it to the committee for final approval.

In two months: Proposal is submitted to the board of trustees for approval.

As individual disciplines write their plans, they will identify the uniqueness of HIV disease in children and how their roles overlap. This should justify the necessity for the interdisciplinary team in managing HIV care.

II. ADMINISTRATION

In most hospitals, the administration oversees many of the departments and support services that will be involved in the HIV/AIDS program. Therefore, the administration will be drawing up a plan for each of these departments or services, such as public relations, development, admissions, housekeeping, X-ray, infection control, staff development, chaplains and child life.

Purpose

State the administration's intent regarding the new HIV/AIDS program, based upon the mission statement of the hospital. State concisely what the administration will do, and why.

EXAMPLE: *To support the initiation and continued operations of our new pediatric HIV/AIDS program, Anytown Children's Hospital administration will provide the appropriate management and support services needed for the program to deliver care in accordance with the hospital's stated mission.*

Goals

Establish what you want to achieve in relation to this program. Derive your goals from the planning committee's work. Refer to the planning guide and borrow from those tasks.

EXAMPLE: *To begin the HIV/AIDS program, within six months the administration will need to:*

- *During the first month, educate the board of directors and trustees to gain approval for the proposed program.*
- *In six weeks, orient the public relations department staff about the new program, and facilitate their outreach to community leaders and related community service facilities.*
- *Over the next two to three months, rally hospital employees' support through education.*
- *Inform and mobilize involved departments to become oriented to the plan, facilitate detail planning, procure resources, implement departmental education, and assure that resources are ready for implementation.*

Objectives

As in the planning committee guide, you too will need to write the objectives for attaining the goals you have set.

EXAMPLE: *To begin the HIV/AIDS program within three months, the administration will need to:*

1. Prepare the proposed budget.

2. Obtain board of trustees approval.

3. Prepare public relations and development departments.

4. Raise funds.

5. Begin campaign to educate: political leaders, general public, schools, and related facilities and services.

6. Begin the planning process for involved departments.

7. Update organizational structure (if changed), identify positions.

8. Apply to alternate funding sources.

9. Establish hospital policy related to HIV and consider:

- *infection control*
- *HIV testing and documentation of results*
- *privacy, confidentiality issues*
- *employee health and mental health services*
- *employees' responsibility to provide care*
- *duration, interval, and frequency of vacations for employees working exclusively with patients infected with HIV.*

Task Identification

List the tasks that need to be accomplished to achieve the above objectives.

1. Budget: delegate to accounting with 2-week deadline.

2. Board of Trustees approval: seek and obtain within one month; submit budget for approval for the proposed program.

3. Public relations: orient the public relations department staff; set up seminar time with clinicians and administrator; delegate planning for public relations campaign; facilitate outreach activities.

4. Raise funds: delegate to development department.

5. Education: delegate to public relations to organize a speakers bureau for professional groups, schools, community health services, parent groups, delegate to staff development for hospital staff.

6. Update organizational structure: include HIV program on organizational structure, amend wiring diagram, identify new program positions, document job descriptions, and inform department heads.

7. Initiate departmental planning for new program:

- Orient department heads to the HIV program plan (critical departments to include: admissions, business office, chaplains, child life, dietary, housekeeping, infection control, laboratory, occupational/speech/physical therapy, pharmacy, volunteers)
- Disseminate planning guide
- Field questions, clarify concerns
- Delegate the planning charge with deadlines
- Reconvene group, verify plans
- Prepare for implementation

8. Assign assistant to develop related policy:

- Research local and state laws and regulations to determine applicability to the new HIV program
- Develop policy on the issues recommended by those experienced in the pediatric HIV field, such as employee vacations, employee health services (including mental health), universal precautions, confidentiality, staff development and continuing education, etc.

Develop a time schedule

Take your list of tasks and place them on the planning guide (Figure 3-1, page 24) in the order of their priority. Identify the start times for each task, and the discipline or department to which the responsibility is assigned.

III. PHYSICIANS

Purpose

In keeping with the mission statement of the hospital, state the medical purpose for forming this service for infants, children and adolescents with HIV infection; describe the program you envision.

EXAMPLE: *The medical department of Anytown Children's Hospital is expanding its services to provide general and specialty medical care to patients in the HIV/AIDS program.*

Goals

Establish the goals you plan to attain through the formation of this service to HIV positive children. Address the critical program components:

- Child-centered, family-focused
- Interdisciplinary team work
- Access to community-based care over the continuum of the child's experience with HIV infection
- Access to AIDS Clinical Trial Groups
- Care for the caregivers
- Community support for the program

EXAMPLE: *To establish and maintain a child-centered, family-focused medical service for children with HIV infection, immunology and infectious disease specialists will be an integral part of the core interdisciplinary team providing chronic illness care throughout the continuum of infection with HIV.*

Objectives

Name the planning objectives needed to accomplish the goals you have set. Include objectives that will address such issues as policy formation, protocol development, team building, medical super-specialists, community and staff education.

EXAMPLE: *For the first goal listed above: To establish and maintain a child-centered, family-focused medical service for children with HIV infection, we will:*

1. Design our facility to allow enough space and appropriate equipment to see the child and the HIV-infected parent simultaneously.

2. Extend medical staff privileges to the appropriate provider(s) of care for the HIV-infected parent.

3. Establish referral and service networks for both the child and parent.

4. Provide input to administration regarding policy development that may provide for the care of HIV-infected mothers within the parameters of our HIV program.

Task Identification

List the tasks to be accomplished to implement the objectives and determine the priority for each one.

Timeline

Put all the tasks on the planning guide (Figure 3-1, page 24) in the order of their priority.

IV. NURSING

Purpose

State the nursing purpose for forming this service for children/adolescents with HIV infection. Highlight the difference in this program compared to that of any other hospital-wide nursing area. The purpose statement should clarify why you have taken on this mission.

EXAMPLE: *The Department of Nursing has designated a specific team of nurses to care for children with HIV infection for the purpose of insuring that the highest degree of quality and coordination of care is delivered. The team will provide coordinated, compassionate, state-of-the-art nursing care to these children/adolescents*

in ongoing collaboration with the interdisciplinary health and social service team.

Goals

Establish the outcomes you expect from this service to HIV-positive children. Include the critical components of a comprehensive program.

EXAMPLE: *With additional education, experience, and sensitivity training, this team will provide the coordination for a significant portion of the complex care needed by HIV-infected children. The Department of Nursing, Anytown Children's Hospital, has developed the following HIV nursing care team goals to accomplish our mission and fulfill our purpose:*

- *To establish a system that cares for HIV-positive children throughout the continuum of infection.*
- *To establish a support system for the caregivers of those children so they will sustain their maximum abilities to provide care.*

Objectives

List the objectives that define how and when you will accomplish the nursing goals.

EXAMPLE: *The objectives that will lead to accomplishment of the two goals above include:*

1. To design the HIV program of nursing care to cover:

- *Prevention; detection; education to prevent opportunistic infections; and care during medical treatment*
- *Promotion of development during periods of health; education to maximize a healthy lifestyle; preparation for dying and death; and support for coping with bereavement*

2. To document policy and establish procedures for sustaining the caregivers to include:

- *month-long, uninterrupted, annual vacations*[9]
- *regularly scheduled mental health support*
- *semiannual continuing education*
- *accessible employee health services*
- *sufficient ancillary nursing personnel to carry out the non-nursing assistive tasks*

Task identification

List the tasks to be accomplished to reach your stated objectives, and determine the priority for each one.

Timeline

Put all the tasks on the planning guide (Figure 3-1) in the order of their priority.

V. SOCIAL WORK

Purpose

State the purpose for forming this service of psychosocial intervention for children/adolescents with HIV infection. In your purpose, differentiate the factors that require unique psychosocial intervention when a child and usually another family member is HIV positive.

EXAMPLE: *This special social work team is established to provide comprehensive, culturally relevant, continuous (from*

identification of risk status through testing, diagnosis, disease progression, and death), humane and nondiscriminatory medical-psychosocial care of children/adolescents with HIV infection and their families.

Goals

Establish the goals you plan to attain through the formation of this service to HIV-positive children.

EXAMPLE:

- *Provide broad scope of psychosocial interventions to assist the family to cope with HIV infection in one or more of its members.*
- *Encourage at-risk, infected, and diseased populations to modify behaviors implicated in the development and transmission of HIV infection.*
- *Provide advocacy services while maintaining confidentiality for children and families.*
- *Provide interventions, such as education, family therapy, community organization, group therapy, behavior modification, and social skills training as well as more traditional therapies to modify behaviors that contribute to transmission of the HIV.*
- *Provide interventions for a family whose normal family life has been disrupted, without introducing more chaos.*

Objectives

List the objectives you will need to achieve to accomplish the social work goals. Be practical in setting behavioral, measurable, attainable objectives.

EXAMPLE:

1. Assume a leadership role in the hospital and community to organize and facilitate HIV education programs aimed at dispelling fear and preventing transmission of HIV infection.

2. Include the sibling(s) who are not HIV-infected in family psychosocial interventions regarding preventing risk behaviors.

3. Provide periodic updates on the current state and federal laws relating to children/families with HIV infection, to assure that social work staff is aware of the law

4. Advocate for the family in cases when called upon to sign release of medical records to outside sources, or when families express reticence when requested to participate in research studies.

Task identification

List the tasks to be accomplished before starting the program, and determine the priority for each one. Plan for:

1. Recruiting and hiring social work staff (1 social worker for up to 60 symptomatic children).

2. Identifying private space to maintain confidentiality during counselling sessions.

3. Accumulating resources for outreach and referral such as community agency directory; municipal, county and state assistance offices; information and referral sources; laws and regulations, etc.

4. Gathering supplies and equipment including assessment tools and references; policies and procedures of your hospital

and related community, and case management agencies.

Timeline

Put all the tasks on the planning guide (Figure 3-1, page 24) in the order of their priority, with periodic reminders to keep the hospital HIV/AIDS committee appraised of your function.

Implementation

The implementation phase of this HIV program development is the time when the vision becomes reality. Use the planning guide as your implementation tool to perform the tasks necessary to actualize the plan. Schedule weekly meetings to assure coordination of task accomplishment and ongoing communication for problem solving during project implementation. Department heads and possibly the planning committee will be likely attendees at these meetings.

The planning committee's work has been accomplished and can be disbanded at this point. However, concurrent activity will be occurring in each department, and you may wish to retain the committee as an advisory group throughout the implementation phase to monitor progress and facilitate communication.

For example, the planning committee might provide appropriate assistance in monitoring the schedule and facilitating timeliness of task accomplishment. Since these committee members know the parameters of the total project, they will have insight regarding the relationship of the individual tasks to each other and to the project goals.

Later, during the evaluation phase of the project, the planning committee would be most helpful in the evaluation process as you answer the question "Did we do what we set out to do?"

Evaluation

The essence of evaluation is systematically answering the questions: Did we do it? Have we accomplished our mission? Have we fulfilled our purpose? Have we attained our goal(s)? Have we met our objective(s)? The appropriate time for departmental and hospital-wide evaluation will vary. Usually departments plan annual evaluations, and hospitals evaluate for accreditation cycles.

For this new HIV/AIDS program, annual evaluation is important to validate mission and purpose, and to keep current on the incidence and prevalence of HIV in your community. For the early years of the 1990s, as new discoveries are made in the HIV field, it will be essential to perform community assessments and programmatic and departmental evaluations to remain abreast of the current developments in the field.

Each department or discipline that wishes to evaluate its performance in setting up the HIV program should take all planning materials and use them as a baseline for evaluating the outcome achieved within the area. The process involves asking and answering the above questions. A format that will be helpful in conducting your evaluation is depicted in Figure 3-2, page 33.

Procedure

Take the evaluation guide (Figure 3-2, page 33) and expand the space as needed to address the individual components of each section. For instance, your mission or purpose may fit into the three lines available, but your "goals" section may require several pages to list all of the goals for your

department. The "objectives" section may require more space, since all the tasks you have listed to be accomplished in the plan will be entered in the "action" column next to each objective to which it is related.

Mission statement. Place your hospital's mission statement relating to the HIV/AIDS program in the top left hand column and list the action taken to implement that mission in the adjacent column. In the "outcome" column list the results of your actions (administration, medicine, nursing, social work) related to the mission.

For the "evaluation" column describe your judgment of mission accomplishment. Has it been filled? Has it been partially fulfilled? Have you just begun? Is it an ongoing mission, something that will be finished only when HIV/AIDS is eradicated? Record your evaluation.

Purpose. Place your department's planned statement of purpose in the extreme left box. List the actions you had planned to take to accomplish that purpose. In the next column under "outcome" list the actions you actually took to implement your purpose. Record your evaluation.

Goals. List your department's planned goals and actions. Next, identify the outcome you have experienced related to each of the stated goals. Evaluate whether or not each goal was accomplished, and if you need to add to the list for your next evaluation period.

Evaluation Guide

Plan	Action	Outcome	Evaluation
Mission			
Purpose			
Goals			
Objectives			

Figure 3-2. Evaluation Guide

Objectives. After you have listed your department's planned objectives and actions in the first two columns, list the outcome for each objective. Have things occurred as planned? Have you met each stated objective? Have these objectives facilitated meeting your goals? Record your evaluation.

Once each department evaluates its own portion of the HIV/AIDS program, involved department heads should meet and take a comprehensive look at the project. You need to reassess your community and the changes it has undergone over the past year. Look closely at the incidence and prevalence of HIV infection, the population acquiring infection, and the changes in type and number of services now available to infants, children and youth. To provide a baseline for continued planning and development, these evaluations will be invaluable when the hospital board and management engage in strategic planning and consider whether to continue the HIV/AIDS program.

The next chapter provides summaries of ten HIV/AIDS programs for children and adolescents across the nation. These programs incorporate the key components described in chapter 2; however, the descriptions outline only the areas in which each is unique. □

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2. Scott, G. B. (1988, May). Clinical Manifestations of HIV Infection in Children. *Pediatric Annals*, 17(5), 366, 368.

3. Novello, 13.

4. Author's note: AIDS Clinical Trials Groups are government funded studies of the effects of new drug treatments on humans. Although no cure has been found, beneficial effects from the new AIDS drugs have been documented and publicized, therefore more and more patients and families want to be involved in the chance to extend their hopes for life and a cure. The government agencies participating in these studies include the Federal Drug Administration, National Cancer Institute, National Institute for Allergy and Infectious Diseases, and National Institutes of Health.

5. *The New York Times.* (1987, April 22). Arson Damages Disputed Foster Home in Queens. Section A, p. 1, column 3.

6. U. S. Department of Health and Human Services. (1987). *Report of the Surgeon General's Workshop on Children With HIV Infection and Their Families*. Rockville, MD: Division of Maternal and Child Health. 39.

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Chapter Four

Programs In Action

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Pediatric AIDS programs already established in the U.S. are located primarily in large cities on the east and west coasts, and the larger midwestern cities where the CDC has identified the largest numbers of children with AIDS. The ten hospital pediatric HIV/AIDS programs visited, for the development of this Sourcebook, often evolved in response to the emerging needs of children infected with HIV who became part of these hospitals' patient population.

Today, there are varying forms of pediatric HIV/AIDS programs. For example, ambulatory care to HIV/AIDS patients is often provided in a designated clinic, while inpatient HIV/AIDS care is integrated with other services. Hemophilia programs tend to integrate care for all their hemophiliac children, including those with HIV infection, both on an inpatient and outpatient basis. Although there are structural variations across programs, all are organized to provide a child-centered, family-focused, comprehensive program of

care and treatment to the children they serve. A complete list of the critical components required to develop programs for HIV-infected children and their families (Appendix D) was compiled during the preparation of this *Sourcebook*. It combines recommendations based upon the ten programs profiled in this chapter.

Presented here are summaries of the ten sites where significant numbers of children and adolescents are receiving care for their HIV infection. Included is a brief description of each hospital, its community, the evolution of the HIV/AIDS program, its size, structure, and financing. The seven children's hospitals described are all voluntary, not-for-profit facilities. The programs are presented in geographical sequence from east to west.

Adolescent AIDS Program Montefiore Medical Center Bronx, New York

HOSPITAL

The Adolescent AIDS Program is associated with the Division of Adolescent Medicine at Montefiore Medical Center, Henry and Lucy Moses Hospital Division. The Medical Center is affiliated with the Albert Einstein College of Medicine in the city of New York, and provides a range of primary, secondary and tertiary medical care.

COMMUNITY

Located in a densely populated, urban residential area in the Bronx, Montefiore serves its ethnically mixed community of blacks, Hispanics and whites.

EVOLUTION

The Adolescent AIDS Program was developed to attend to the previously unmet health care needs of high-risk adolescents in New York City at a time before many teenagers were reported as having AIDS. A high percentage of youth at risk by virtue of sex and drug practices were first identified in a health care needs study conducted by Karen Hein, MD and others, in 1986. Once these needs were identified, Dr. Hein officially opened the program in 1987 and recruited a multidisciplinary staff. Over the next 2 1/2 years, adolescents in need of comprehensive services for health and psychosocial problems arising from HIV infection, were referred, evaluated and followed. Nine separate study grants from various sources supported the services and research until the summer of 1989. The program has now been awarded a Pediatric AIDS Health Care Demonstration Project three-year funding grant by the Bureau of Maternal and Child Health and Resources Development.

Adolescent AIDS Program clinical services are offered daily, with one special clinic day each week in the outpatient department of the hospital. This part of the program is called the Risk Evaluation Program (REP), where a thorough history and assessment for each adolescent is documented. The clinical care is provided by a multidisciplinary team offering care and treatment to ill and at-risk adolescents seeking care and counselling about HIV infection. All staff and consultants attend weekly conference and planning sessions, where the status of each adolescent is reviewed, and intervention plans are made.

Core planning and consultation

At the weekly interdisciplinary staff planning sessions, the clinical progress/status of patients is updated, care planning is coordinated, and research activities and as-

signments are reviewed for clarification. The attendees include physicians, nurses, social workers, epidemiologists, outreach interviewers and community psychologists. Following the planning sessions, the team conducts infectious disease case conferences. The clinical staff presents cases to the consultants (lawyers, child and adult psychiatrists) for problem solving, care planning, and for new insights and approaches to the issues.

Patient population

The patients fall into four distinct groupings: those not at risk who want information; teens whose sero status is unknown; seropositive asymptomatic adolescents; and those with HIV-related illness and AIDS. The involved teens developed their own advertising brochure to tell others about the program. About half the patients are "street kids" who are disenfranchised and have multiple service needs.

Over the last several years, the staff and patients have taken education to the streets in the form of the AIDS Risk Reduction Education and Skills Training (ARREST) program, first developed by health psychologist Michele Kipke (grant funded).

ARREST has reached out to 13 to 15 year-olds in community-based programs in the Bronx to help them learn how to practice healthy behaviors. The program teaches adolescents both the concept of reducing their risk of becoming infected with HIV, and the "how-to" of behaving in a less risky manner. Components of the program's curriculum include learning through role-playing and practicing communications skills, assertiveness behavior, decision-making, negotiating, and self-protection. ARREST actively enlists adolescents in the learning process to increase their repertoire of healthy behaviors—especially focused on AIDS prevention. After evaluating ARREST as a research intervention tool, the risk reduction program is now adapting ARREST for use in clinical intervention for HIV-positive youth.

School and community outreach

Outreach to adolescents (throughout New York City, but primarily in the Bronx) will serve as a model for other urban centers as the virus spreads throughout the country. These efforts involve coordinating educational, social and medical services. The staff provides leadership and partnership with community-based organizations and schools.

Research

Current research projects include a longitudinal study of HIV infection in adolescents, a study comparing education and behavioral interventions, and a statistical and behavioral profile of HIV-positive versus HIV-negative adolescents.

Public Policy

The program provides consultation and advocacy to international, national, federal, state and local groups, both in the public and private sectors, regarding adolescent HIV/AIDS issues.

SIZE

In the clinical component 45 to 50 patients are followed by three full-time equivalents (FTE). The research and advocacy components are fulfilled by a team of 6.0 FTE:

Clinical	Technical Assistance, Advocacy, Research
1 FTE Physician	1 Program Director
1 Nurse Practitioner	1 Administrator
1 Social Worker	1 Health Educator
	1 Epidemiological Interviewer
	1.5 Secretary
	0.25 Biostatistician
	0.25 Data Clerk

FINANCES

The majority of funding sources have been private, with some state grants for research and service. As of October, 1989 the program has become a Pediatric Demonstration Project funded by the Bureau of Maternal and Child Health and Resources Development, Human Resources and Services Administration.

STRUCTURE

Figure 4-1 depicts Montefiore's Adolescent AIDS Program organizational structure.

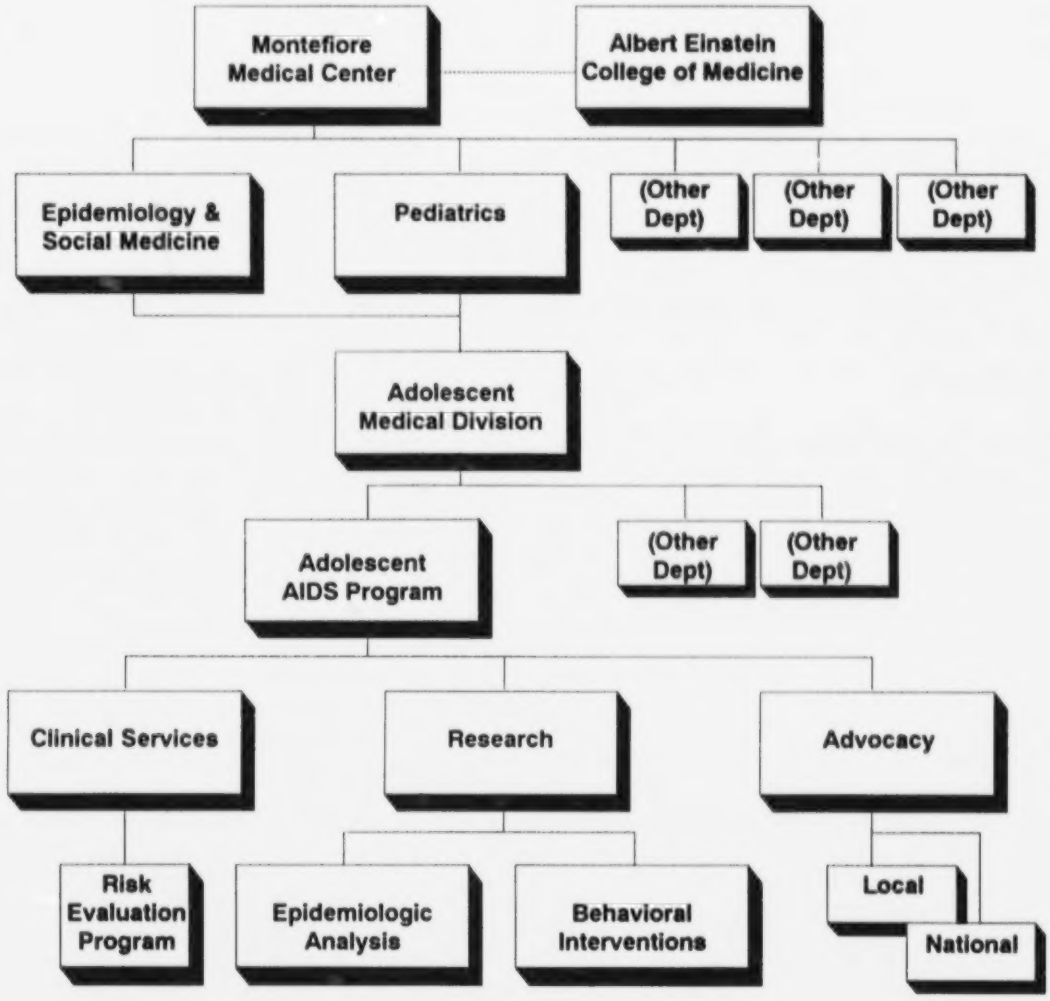

Figure 4-1. Organizational Structure of Montefiore's Adolescent AIDS Program

Harlem Hospital Pediatric AIDS Program, New York, New York

HOSPITAL

Harlem Hospital Center, a public, 1,000-bed general hospital, is part of the New York City Health and Hospital Corporation. Harlem's academic affiliation is with Columbia University in the City of New York, College of Physicians and Surgeons, and the School of Nursing.

COMMUNITY

The hospital is located in the black community of Harlem, which is in the upper Manhattan Island area of New York City.

EVOLUTION

Children with AIDS were first identified at Harlem in 1982. The increasing number of HIV-infected children coming to Harlem lead to the creation of an active program for their care by 1985. As early as 1987, the pediatric unit began becoming home to HIV-infected children whose parents were unable to care for them.

According to Margaret Hegarty, MD, Chief of the Pediatrics Department, the issues relating to the extended hospitalization of children with HIV infection include: absence of parents; delayed discharge; alternative-placement barriers; emotional and developmental stress; unnecessarily long duration of stay; inflated costs; and minimal reimbursement.

Building on this experience, the pediatric medical staff formed a core multidisciplinary team known as the A-Team to provide inpatient and ambulatory care to HIV-infected mothers and children. This approach includes:

- Emphasizing caregiving rather than investigating
- Being open and non-judgmental
- Meeting the patients where *they* are
- Being available and accessible, beyond the one clinic day per week

Genuinely caring

- Being open to unique approaches
- Demonstrating commitment to children

The general pediatrics orientation of the program is implemented by providing ongoing health care (medical, nursing, psychosocial) to mothers and children following the chronic illness model. The staff is committed to model "caring." A standing order from the department chief for all who care for HIV-infected children is to give at least one hug a day per child.

The A-Team holds clinic twice each week in a building across the street from the main hospital. One additional treatment session is held weekly for children receiving intravenous medications.

SIZE

The A-Team staff includes:

Staff		As Needed	
1	Pediatrician, FT	2	Obstetricians
3	Pediatricians, half-time	1	Certified Nurse Midwife
2	Nurses, FT	1	Infectious Disease Specialist
1	Psychologist, FT	1	Social Worker
1	Social Worker, FT		

The A-Team patient load includes:

- Over 200 children referred, and
- 100 HIV-positive children being followed

STRUCTURE

The A-Team is part of the pediatrics department, one of the several departments of medicine. Figure 4-2 depicts the organizational structure of the program.

FINANCES

Harlem is a public hospital funded by tax revenues. Part of the support for the HIV program comes from the Bureau of Maternal and Child Health and Resources Development. Funding for antiretroviral therapy is provided by the AIDS Clinical Trial Group program, through NIH. Medicaid is the payment source for 97 percent of the children receiving care.

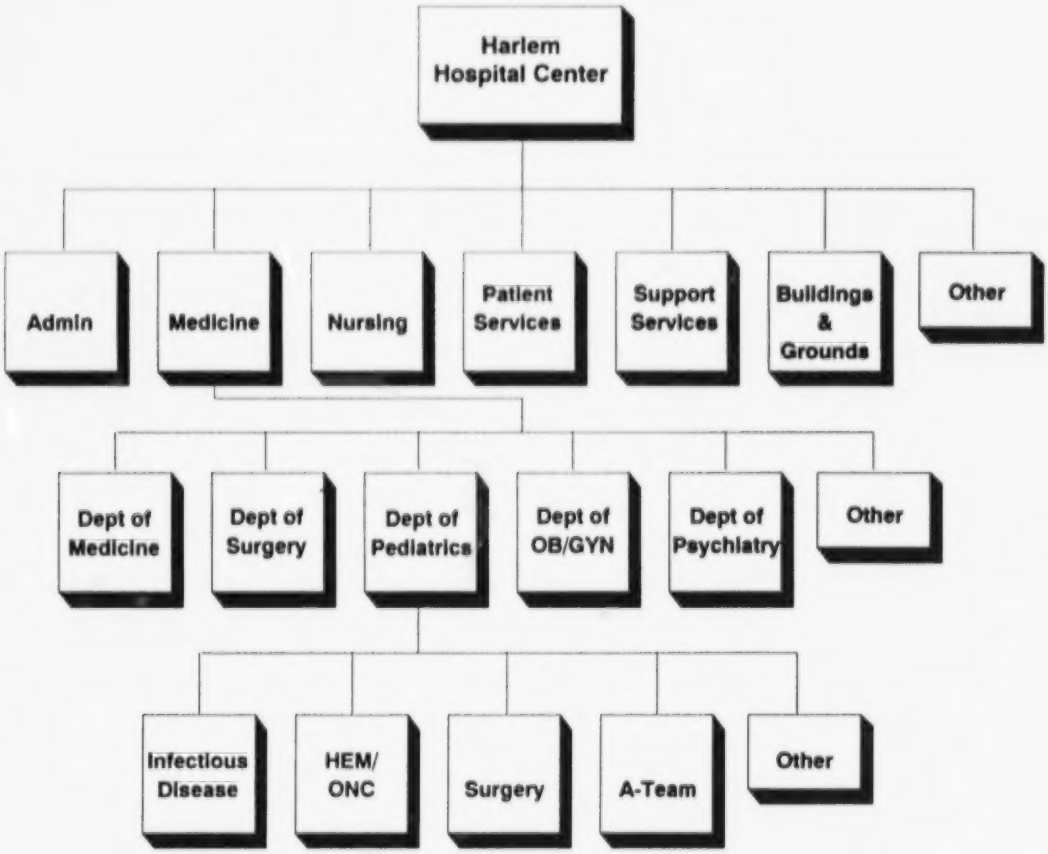

Figure 4-2. Organizational Structure of Harlem Hospital Center

Children's Hospital AIDS Program (CHAP), Children's Hospital of New Jersey, Newark, New Jersey

HOSPITAL

Children's Hospital of New Jersey is a unit of the United Hospitals Medical Center, a teaching affiliate of the University of Medicine and Dentistry of New Jersey, located in the city of Newark. It is a pediatric hospital serving the immediate community for general and specialty pediatric care and the greater state-wide community for referrals.

COMMUNITY

The hospital is located in the northern part of Newark's center city, in a residential area of both single and multi-family dwellings. The population base is largely black and Hispanic.

EVOLUTION

Since 1981, before CDC first reported AIDS in children, Children's Hospital staff has been caring for HIV-infected children and developing HIV-related services. In the mid-1980s, the Children's Hospital AIDS Program (CHAP) was established to provide "state-of-the-art medical care in a loving and dignified manner" to children with AIDS. The "chronic illness model" was adopted and a comprehensive community-based, child-centered, family-focused program for children with HIV infection was developed.

CHAP employs the team approach to care. This approach includes not only those in the professional disciplines who provide health and social services, but also the family and friends of the HIV-infected child. Throughout diagnosis and treatment, the team effort focuses on keeping the child at home and assisting the family in coping with the chronic illness of HIV infection.

Extended team members include those from the Division of Youth and Family Services, the Visiting Nurse Association, home health agencies, Special Child Health Services and the AIDS Resource Foundation for Children. Working together with the CHAP team, these individuals provide support to multi-problem families. They provide transitional care, home care services, and advocacy/education to schools, community agencies and the general public on behalf of children with HIV and their families.

In 1985, the need to provide therapeutic and educational services to children with HIV infection caused the extension of Early Intervention Program (EIP) services to the CHAP population. Aggressive treatment to minimize developmental delays was instituted during the first year, after which the program grew more flexible to meet not only the needs of children, but also the needs of their families.

The success of this program rests in its variety and flexibility. Three services are offered both in patients' homes and in the EIP center:

- Developmental evaluations and individualized developmental plans in cognitive, language, motor, self-help and social-emotional skill areas
- Developmental play sessions to facilitate socialization, stimulation, and normalization

- Support services to families: peers and professionals provide emotional and educational support through both group and individual interactions during HIV infection, illness, and finally death of one or more family members.

CHAP team members cooperate in research and writing, and provide the health care community with medical, nursing and other health care literature on the care of children with HIV infection. As a resource, CHAP members are extensively involved with public and professional education on various aspects of care for pediatric HIV infection. CHAP provides information to health care providers seeking to establish or expand services to HIV-infected children. It also offers on-site clinical experience to physicians, nurses, and social workers.

The National Pediatric HIV Resource Center was established at CHAP in 1989 to inform, guide and assist health care professionals and organizations across the country in caring for HIV-infected children and their families. Included in the services offered are:

- Clearinghouse for materials on pediatric HIV infection not traditionally available. (This *Sourcebook for Caring* is an example of this serice.)
- Telephone consultation with professionals at CHAP
- Formal consultation to programs and agencies
- In-depth, professional, multidisciplinary orientation to the care of HIV-infected children
- Legal technical assistance
- Directory of health services for HIV-positive children

SIZE

CHAP team core members include:

- 1 Program director (RN)
- 1 Pediatric immunologist
- 3 Infectious disease specialists
- 4 Nurses - hospital and home care
- 1 Clinical nurse specialist/PNP
- 2 Outreach educators (RN)
- 3 Social workers
- 1 Nutritionist

Others participating in specialty areas of care include:

- Child development specialists
- Speech/language/hearing therapists
- Dentists
- Ear/nose/throat specialists
- Hematologists
- Neurologists
- Gastroenterologists
- Pathologists
- Surgeons

The cumulative number of patients seen at CHAP is 250. Over 200 children are currently being followed.

- 40 are AIDS cases
- 160 are HIV positive

STRUCTURE

CHAP is a structured program within Children's Hospital's medical Division of Allergy, Immunology and Infectious Disease. Figures 4-3 and 4-4 depict the organizational structure of the program and the interrelationship of its multidisciplinary services.

FINANCES

Private, state, and federal funding sources support the programs in CHAP.

Those sources include:

- The U. S. Bureau of Maternal and Child Health and Resources Development
- Centers for Disease Control
- National Institutes of Health
- New Jersey Department of Education
- New Jersey State Department of Health
- New Jersey State Department of Human Services, Division of Youth and Family Services

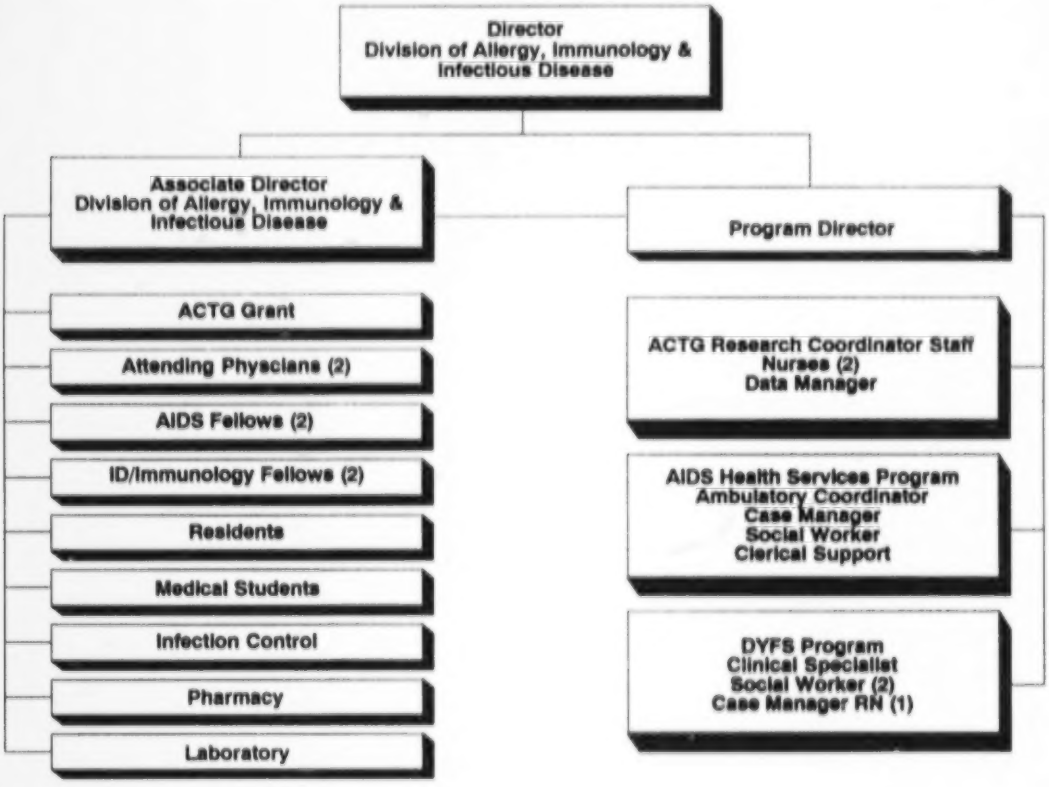

Figure 4-3. Organizational Structure of Children's Hospital AIDS Program (CHAP)

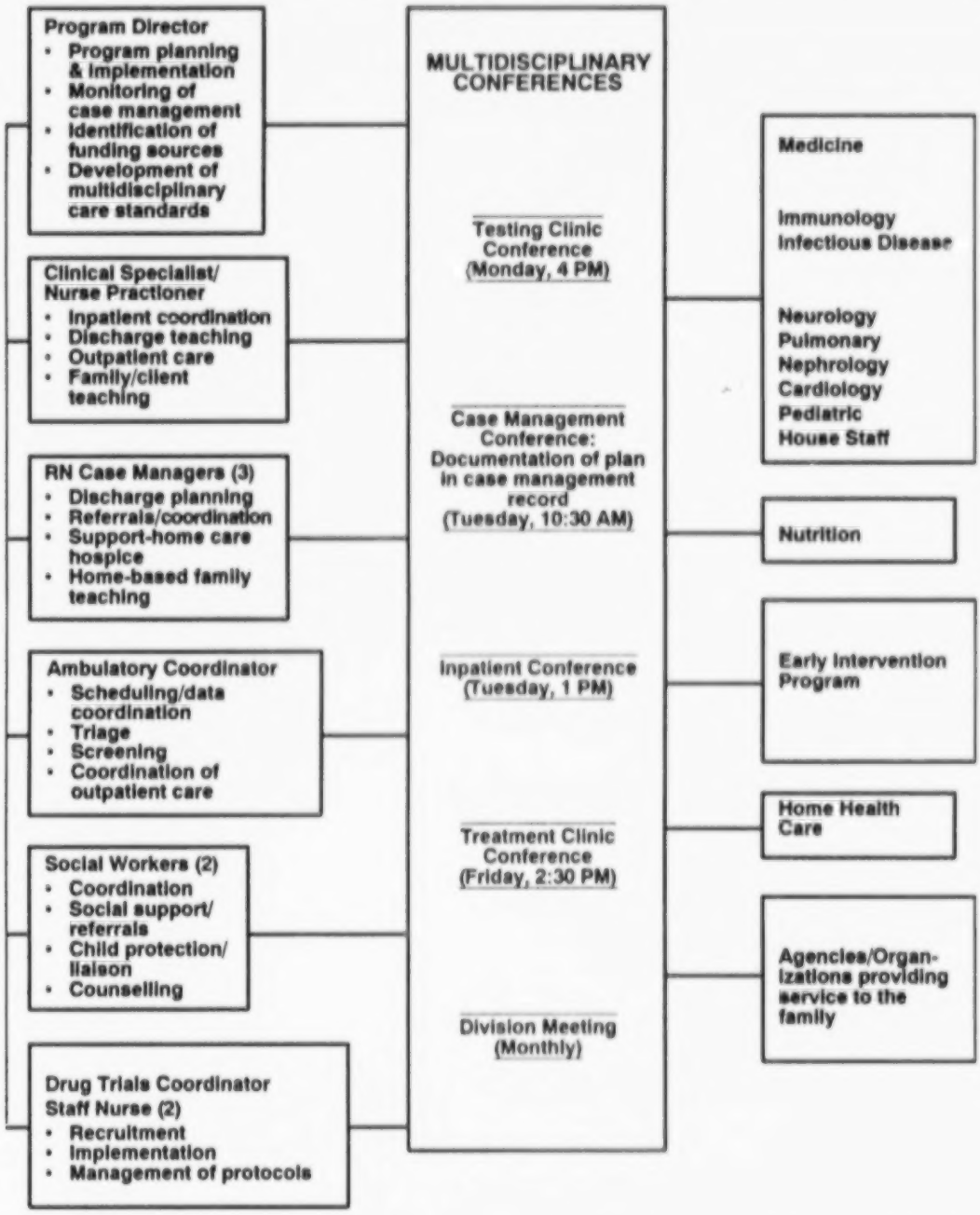

Figure 4-4. Interrelationship of Multidisciplinary Services, Children's Hospital AIDS Program (CHAP)

Mt. Washington Pediatric Hospital, Baltimore, Maryland

HOSPITAL

Mt. Washington Pediatric Hospital (MWPH) is a 130-bed pediatric rehabilitation and specialty hospital in Baltimore. It has recently opened a 50-bed satellite facility in another area of the city. MWPH provides a continuum of comprehensive pediatric rehabilitation services to medically fragile children whose health care needs go beyond short-term acute care. MWPH services reach into the community through its Home Health Agency which provides professional and support services to children and their families with illnesses requiring nursing assessment and treatment in the home, home-based rehabilitative services and parent training for home care.

COMMUNITY

MWPH is situated in a residential neighborhood in northwest Baltimore, atop a wooded knoll; however the majority of HIV-positive patients referred to MWPH are from the Baltimore inner city. The hospital's catchment area includes not only Baltimore and the southeastern counties of Maryland, but also serves patients referred from the District of Columbia, Virginia, Pennsylvania, New York and as far away as Wisconsin.

EVOLUTION

MWPH began receiving referrals for children with HIV infection who were admitted with a primary diagnosis of another chronic illness and/or chronic pulmonary disease (bronchopulmonary dysplasia). Johns Hopkins Hospital and the University of Maryland Medical System now refer children to MWPH for antiretroviral therapy under their own protocols.

Care of HIV-positive children is integrated throughout the hospital. No exclusive program nor inpatient unit has been designated. Infection control is maintained with universal precautions. Since caring for its first HIV-positive child in the mid-1980s, the nursing staff has developed standards of practice and protocols for the care of HIV-infected patients.

The largest number of outpatients with HIV infection are cared for by the hospital's Home Health Agency. Patients are generally referred to the agency directly — from either Johns Hopkins Children's Center, or the University of Maryland Hospital — for AZT therapy and other services, without first being an inpatient at MWPH.

SIZE

Since 1986, MWPH has provided care for at least 25 children with HIV infection in the hospital and in the home health care services. Less than half of those HIV-positive children were classified under the CDC definition of AIDS.

STRUCTURE

As an entity, there is no designated HIV/AIDS program. Care is provided to HIV-infected children through six clinical programs:

- Pulmonary Rehabilitation
- Physical Rehabilitation
- Rehabilitation of Chronic Illness
- Continuing Care
- Respite
- Home Health

The home health care services, pulmonary rehabilitation, and rehabilitation of chronic illness programs presently have the children with HIV infection.

FINANCES

The reimbursement for care of children with HIV infection is provided chiefly by Medicaid. No outside grants support the provision of care to HIV-positive children.

Children's National Medical Center, Washington, D.C.

HOSPITAL

Children's National Medical Center (CNMC) is a 279-bed children's hospital affiliated with the George Washington University School of Medicine in Washington, D.C. CNMC now serves as the largest referral center for HIV-infected children in the greater metropolitan Washington area.

COMMUNITY

CNMC is located near the Washington Hospital Center and the Veteran's Administration Hospital in northwest Washington, D.C. The hospital has served a racially and socio-economically mixed population of HIV-positive patients: 73 percent black, 16 percent Caucasian, and 3 percent Hispanic. Of the officially reported cases of AIDS at CNMC, 50 percent were from the District of Columbia, 36 percent from Maryland, 12 percent from Virginia, and 2 percent from elsewhere.

EVOLUTION

CNMC has been caring for HIV-infected children since the early 1980s. In 1985 an interdisciplinary committee—the Children's Hospital AIDS Coordinating Committee (CHACC)—was formed to address the needs of patients and families as well as ethical and public health concerns accompanying HIV infection. Subsequently, a clinical team known as the Special Immunology Service (SIS) was formed to provide care to the majority of the hospital's HIV-infected infants, young children and their families.

Other hospital departments participate in the care of children with HIV infection. The Department of Adolescent and Young Adult Medicine follows known HIV-infected youth and includes prevention and seroprevalence studies. The Hematology/Oncology Department continues to follow patients already known to them prior to an HIV diagnosis. These programs, in collaboration with representatives of all major hospital departments working on HIV-related efforts, form Children's HIV and AIDS Model Programs (Project CHAMP).

Both inpatient and outpatient clinical services are provided. Research protocols and a model Buddy program are underway. Family-focused, comprehensive case management is provided through coordination with the medical treatment of the child throughout the course of the illness; through bereavement; and beyond. Levels of case management have been identified based on intensity of need. Interagency linkages have been established for sharing case management of the multiple, complex needs of patients.

Late in 1988, the hospital received a Robert Wood Johnson Foundation grant to develop outreach aspects of a model pediatric AIDS service and prevention program. This project provides the following:

- Educational material on pediatric HIV/AIDS infection for volunteers, home care and hospice workers, par-

ents, extended family members, foster care providers, adolescents, and other personnel caring for this population in collaboration with the Academy for Educational Development (see resource list in Appendix E)

- Expanded community outreach efforts to recruit and train volunteers in providing services to HIV-infected children and their families

- A model prevention program for adolescents at high risk for contracting HIV infection, that encompasses educational materials and appropriate medical care and counseling

SIZE

The SIS staff is composed of:

- 2 Physicians, infectious disease
- 1 Clinical nurse specialist
- 1 Registered nurse
- 2 Social workers (MSW)
- 1 Administrative assistant

Complementing the SIS staff is:

- 1 Registered nurse, conducting epidemiology research
- 1 Volunteer coordinator
- 1 Nurse education specialist
- 2 Administrative assistants

Complementing HIV services in other departments are:

- 1 Social worker (MSW) in the adolescent program
- 1 Social worker (MSW) for patients with HIV and hemophilia at CNMC and GW University Hospital

The patients (June 1984 - November 1989) include:

- 257 HIV-positive children and adolescents
- 174 of which are presently receiving services
- 42 of whom have reportable AIDS

STRUCTURE

Although CHAMP is a program of the Children's National Medical Center, it is closely affiliated with the George Washington University School of Medicine in its teaching and research activities.

Figure 4-5 illustrates the organizational structure.

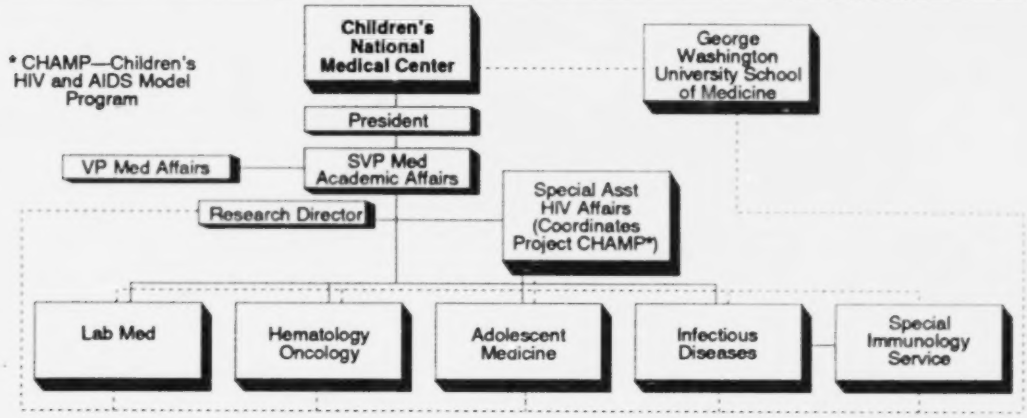

Figure 4-5. Organizational Structure of Children's National Medical Center

FINANCES

Medicaid is the major funding source for medical services. Additional services and research are made possible with funding from the Robert Wood Johnson Foundation, Centers for Disease Control, the Health Resources Services Administration, the National Hemophilia Foundation, the District of Columbia Commission of Public Health, the Devore-Stewart Trust, the Medical Society of the District of Columbia Foundation, and private contributors.

South Florida AIDS Network at Jackson Memorial Hospital, Miami, Florida

HOSPITAL

Jackson Memorial Hospital is a 1,285-bed public hospital affiliated with the University of Miami School of Medicine, Miami, Florida. It is comprised of specialty hospital centers such as orthopedics/neurology/rehabilitation, women's, medical, surgical, pediatrics, and mental health. Of the eight buildings comprising the medical center at Jackson Memorial, the South Florida AIDS Network (SFAN) is housed in the former medical examiners building, an original wing in the hospital.

COMMUNITY

Jackson Memorial Hospital is located on the medical campus of the University of Miami in the city of Miami. Jackson serves both Miami and Dade County, an ethnically-mixed area, including blacks, Hispanics, Caribbean Islanders and whites.

EVOLUTION

SFAN was established in 1986 with a grant from the Robert Wood Johnson Foundation to the Jackson Memorial Hospital through the Public Health Trust of Dade County. As a multi-service and multi-disciplined network, the comprehensive philosophy of care for this institution is reflected in SFAN's membership:

- Eight Primary health care community clinics
- Five community-based counseling agencies
- The Visiting Nurse Association
- Hospice, Inc.
- An adult residential facility
- Children's Home Society foster care program
- Chaplain's interfaith network
- Nursing homes
- A general hospital

Within SFAN is the Pediatric AIDS Health Care Demonstration Project, a new program of SFAN. It was initiated in 1988, seven years after Gwendolyn Scott, MD, diagnosed the first child with AIDS at Jackson Memorial Hospital. The Pediatric Demonstration Project, with its multi-specialty teams consisting of nursing, social work, and case managers, is now following over 150 mothers and their children to administer health care and prevention services. The Pediatric AIDS Demonstration project is collocated with the Substance Abuse/HIV Prevention and Developmental Services sub-project in the Department of Obstetrics and Pediatrics.

SIZE

The staff of the Pediatric AIDS project includes:

- 1 Nurse—co-director of the program
- 1 Social worker—co-director of the program
- 3 Social workers
- 7 Case managers—representative of the community

The patients: Fifty-three percent of the patient population is Afro-American; 30 percent Haitian; 15 percent Hispanic and 2 percent Anglo-Saxon. To date, five mothers have died (four from AIDS-related complications, one from a drug overdose) and six children have expired from AIDS-related illness. Of 139 children involved in the project, 23 are diagnosed as infected with HIV.

The three-pronged maternal-child program provides intensive case management, ongoing education and support counseling, drug rehabilitation, and developmental intervention.

Within the Demonstration Project, same-day obstetric, gynecologic, and pediatric health and social services are provided to mothers and babies. Case managers triage and coordinate the inpatient and outpatient care for a caseload of up to 30 families each (mother and children). Haitian, Afro-American, Hispanic, and Caucasian case management staff reflect the ethnic, gender and racial mix of the community which they serve.

FINANCES

This program is made possible through funding from the Bureau of Maternal and Child Health and Resources Development.

STRUCTURE

The organizational structure is depicted in Figure 4-6.

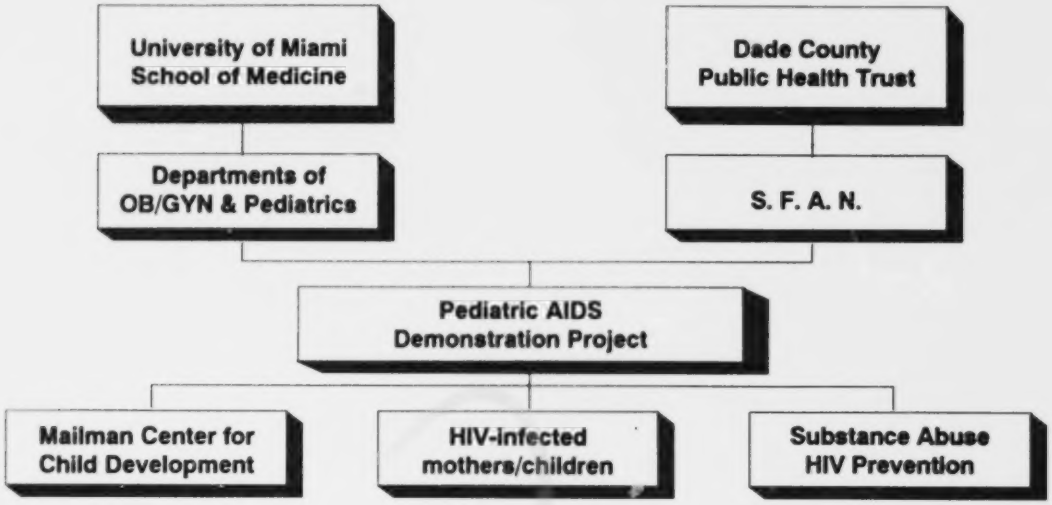

Figure 4-6. Organizational Structure of Jackson Memorial Hospital

Maternal Infant Center for HIV (MICH), Children's Hospital of Michigan, Detroit

HOSPITAL

Children's Hospital of Michigan is a 250-bed facility affiliated with Wayne State University, Detroit. Children's collaborates closely with Hutzel Hospital in its program of care for mothers and children with HIV infection.

COMMUNITY

Children's Hospital is located in the heart of Detroit, on a medical campus with other health and university teaching facilities. The University Health Center serves an ethnically and racially mixed population of patients with a large representation of black and Polish people and some Hispanic and white. Along with six other general and special hospitals (Hutzel included), Children's Hospital is a member of the Detroit Medical Center, Inc. (DMC).

EVOLUTION

In 1985, Children's Hospital physicians began seeing HIV-infected children and noting that their mothers were also in need of care. By mid-1988, the Michigan Department of Social Services financed the transportation needs of patients. Children's Hospital joined with its DMC affiliate, Hutzel Hospital, that serves the mothers of its patients, and collaborates on providing joint service to mothers and babies. Clinic space was secured in the University Health Center where the mothers and their children could be concurrently attended to by their respective health care and social service providers.

In 1988 the state Department of Social Services formalized a Medically Fragile Unit, and placed staff on site with the joint mother-infant program at Children's Hospital. Late in 1988, the MICH Program was formalized, and designated as one of the pediatric AIDS demonstration projects supported by the Bureau of Maternal and Child Health and Resources Development with funding channeled through the Michigan Department of Public Health.

SIZE

Program staff includes:

- 2 Pediatric immunologists
- 1 Developmental pediatrician
- 1 Internist/infectious disease specialist for the women.
- 1 Nurse, pediatric
- 1 Clinical Nurse Specialist, for mothers
- 2 Psychotherapists
- 2 Counselors
- 1 Secretary

Supporting the MICH program activities is staff from the City of Detroit:

- 1 Public Health Nurse from Children's Special Health Care Services
- Medically Fragile Unit—Social Services

Patient population:

- 44 Mothers are being followed with their children
- 40 HIV-infected infants—13 with AIDS
- 46 HIV antibody-positive infants (passive transfer of maternal antibody) being followed through age 3
- 20 of whom are indeterminate, and 12 as yet unseen

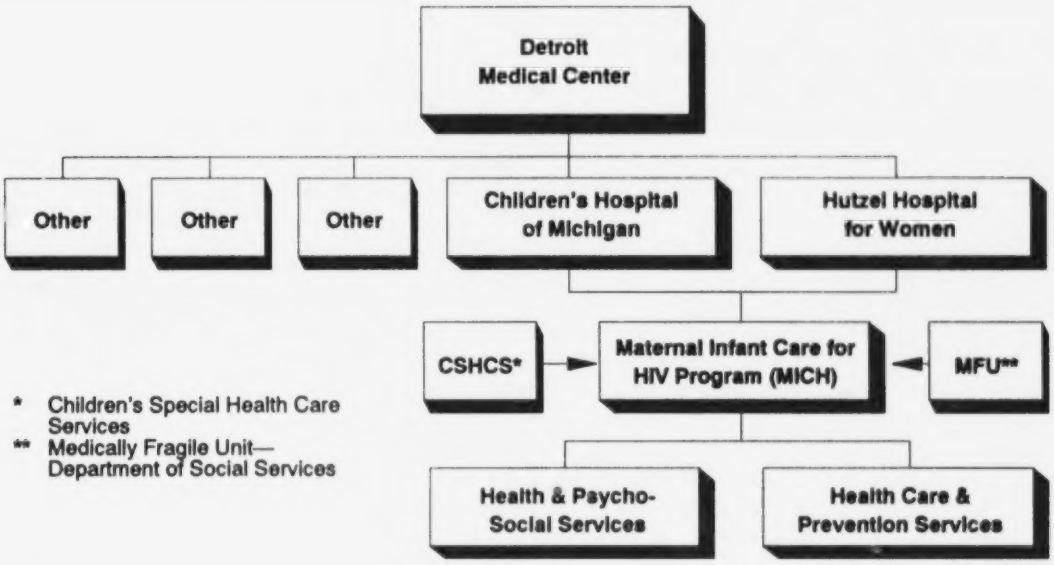

Figure 4-7. Organizational Structure of Detroit Medical Center

At the weekly clinic sessions the team provides care for 15 to 20 children, while mothers are being seen by their physicians. Concurrently the psychotherapists provide individual and group support to the families. Additionally, in the prevention portion of the program at the Hutzel Hospital site, a counselor provides education and counsel for postpartum women who are drug users, and substance abuse counselors provide individual and group therapy. There is a growing weekly support group at Children's Hospital for mothers of HIV-positive children led by psychotherapists and a mother who has been rehabilitated from drugs. Implementation of a second mothers' group is planned for early 1990, along with a support group for caregivers, such as extended family members, foster parents, respite and hospice workers.

Complementing these programs at Children's and Hutzel Hospitals, the Michigan Department of Social Services holds support groups called "Parent Empowerment" for parents of HIV-infected children in the Greater Detroit area. Skills building and systems negotiation are a part of the group's focus.

STRUCTURE

Figure 4-7 depicts the organizational structure of the program at the Detroit Medical Center.

FINANCES

The Maternal Infant Center for HIV is financed by the Children's Hospital of Michigan, the Michigan Department of Social Services, the Bureau of Maternal and Child Health and Resources Development, Human Resources Service Administration, and the Michigan Children's Special Health Care Services.

Special Infectious Disease Clinic, Children's Memorial Hospital, Chicago, Illinois

HOSPITAL

Children's Memorial Hospital is a 265-bed, acute care pediatric facility located on Chicago's north side. Children's is part of the McGaw Medical Center of Northwestern University and provides pediatric diagnostic and therapeutic medical care. It offers 64 general and special clinics in its ambulatory care services department.

COMMUNITY

This gentrified, multi-racial, multi-cultural neighborhood is located just north of the center city, in an area of mostly single-family and some multiple family dwellings. Racially, the HIV-infected patient population includes 60 percent black, 20 percent Hispanic and 20 percent Caucasian children.

EVOLUTION

Among its 64 clinics, Children's Memorial Hospital offers health care to HIV-infected children. The first AIDS patient was identified at Children's in January, 1985. By September, 1987 there were 22 children with HIV infection, and the Special Infectious Disease Clinic was established as a separate entity, co-directed by two physicians. The following month the PNP joined the physicians and the secretary to provide nursing care, coordination and case management for the children being cared for by the team. Two years later in 1989, when the clinic received funding and became an AIDS Clinical Trial Group of the National Institutes of Health, three more nurses and a social worker were added to the staff.

Clinic is held one day each week, followed another day by a team conference in which status reports, problem solving and care planning are discussed. However, the clinic children come into the outpatient department throughout the week seeking care for episodic problems. At these times the children are seen by the available Special Immunology Service nurse and physician.

Inpatient/outpatient coordination of care is accomplished through daily rounds, with the Special Immunology Service team visiting their hospitalized patients. Every two weeks the team meets in a research conference to review the status of children on research protocols and plan for their care. On alternate weeks a staff psychologist conducts a support group for the staff of caregivers working with HIV-infected children.

The social work staff, along with the nursing staff, holds three group sessions for parent support. One group focuses on the grieving process, a second is designed for foster parents, and the third is held for natural parents learning to live with HIV infection in their family.

In addition to seasonal theme parties held for patients and families, the Special Immunology Service offers a 6-week summer day camp for HIV-positive preschool children, led by the Child Life Department. Children gather on the grounds of the hospital three afternoons each week during the summer for camp activities which stimulate growth, development and interaction.

An active networking group has developed through monthly meetings of individuals and groups working with the HIV-positive population in Chicago. This Family and Children's AIDS Network is composed of health care providers, hospitals, social

service and drug treatment agencies, child welfare agencies, and city and state agencies such as the departments of child and family services, and alcohol and substance abuse. Together, this group facilitates communication and coordination, and plans for community initiatives supporting improved care for families and children with HIV infection.

SIZE

The clinic is staffed by:

- 2 Physicians (one full time and one part time)
- 1 Pediatric nurse practitioner
- 3 Registered nurses (two of whom coordinate and implement the protocols)
- 1 Social worker
- 1 Secretary

Professionals from the areas of child life support, home health nursing, social work, physical and speech therapy, pastoral care, nutrition, medical psychology and child psychiatry complement the full time staff.

The patients consist of:

- 114 seen cumulatively
- 21 who have died, 9 in 1989
- 90-95 are being followed; about 60 percent are essentially well children, and 32 of these have seroconverted to negative.
- 38 children are HIV-positive, of whom 22 are classified as indeterminate (P-0)

If children with hemophilia develop HIV-related symptoms and become eligible for AIDS treatment protocols, they are seen by the Special Immunology Service staff in addition to the hemophilia clinic team. The hemophilia nurse continues as the case manager for the children seen by both services.

STRUCTURE

The organizational structure of the program is depicted in Figure 4-8.

FINANCES

The program is funded in part by the hospital, and by the National Institutes of Health. Forty-five percent of the clinic patients are receiving Medicaid assistance; most of the remainder are insured, and some are self-paying.

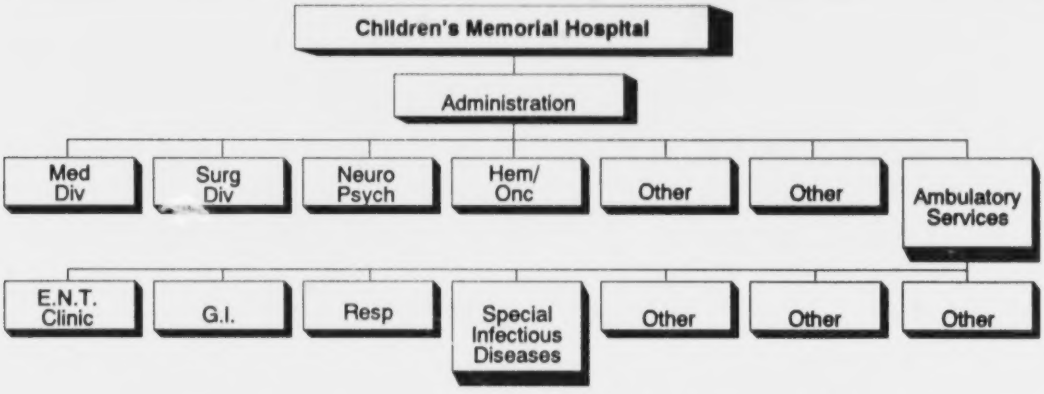

Figure 4-8. Organizational Structure of Children's Memorial Hospital

Los Angeles Pediatric AIDS Network (LAPAN), Los Angeles, California

Supported by a demonstration grant from the Bureau of Maternal and Child Health and Resources Development, the Los Angeles Pediatric AIDS Network was formed under the leadership of Dale Garell, MD, and Marcy Kaplan, LCSW. Nine area hospitals and community-based organizations joined together in an effort to coordinate the management of pediatric HIV cases in the county of Los Angeles. In addition to Childrens Hospital of Los Angeles (CHLA), the membership includes: Cedars Sinai Medical Center, Harbor UCLA Medical Center, Huntington Hospital Hemophilia Center, Los Angeles County/USC Medical Center, King-Drew Medical Center, Memorial Miller Children's Hospital, Olive View Medical Center, and UCLA Medical Center. The LAPAN hospitals also receive funding from the Centers for Disease Control, and the National Institutes of Health.

The Los Angeles Pediatric AIDS Network Coordinating Council (LAPANCC), composed of program physicians and non-clinicians, was appointed to serve as advisors to the member agencies. LAPAN is under the auspices of California Children's Services. Its activities are focused on providing service to HIV-infected children and adolescents and include: promotion of interagency collaboration; education; providing psychosocial intervention; support to foster parents; facilitating service delivery; forecasting future needs for health care services; and the formation of an automated case management system;

The automated case management system is being developed to create a common data base for all participating agencies and hospitals to prevent duplication of service delivery, and to enhance the utilization of services among its members.

To increase communication and interagency sharing of information, the group has developed the Los Angeles Pediatric AIDS Consortium which meets monthly to discuss clinical, statistical and programmatic updates of important activities in the field.

One LAPAN member is highlighted here:

Pediatric AIDS Treatment Center, Childrens Hospital of Los Angeles

HOSPITAL

Childrens Hospital of Los Angeles (CHLA) is a 331-bed hospital affiliated with the University of Southern California. It began the first pediatric HIV/AIDS program in Los Angeles County which is under the umbrella of California Children's Services Treatment Center.

In addition to providing direct health and psychosocial care, the Pediatric AIDS Treatment Center staff participates in research, education and community outreach to schools, parent groups, day care centers' staff and parents, and other professional groups. Social workers provide outreach and community education largely focused on psychosocial issues and strategies for intervention for families infected with HIV.

COMMUNITY

CHLA is located in the northwestern part of Los Angeles in a mixed commercial/residential area. It provides tertiary

level care to a mixed ethnic population chiefly from the southwest. The hospital also operates a satellite family practice clinic about 90 miles away, in the city of San Bernadino.

EVOLUTION

The Pediatric AIDS Treatment Center at CHLA was developed during the late 1980s. The Treatment Center is composed of three clinics: hemophilia, immunology and adolescent. The hemophilia program began identifying HIV-infected patients in July 1982. In the pediatric clinic, the first HIV-infected patient was identified in 1983.

To follow through with issues arising from these new cases, the hospital formed the AIDS subcommittee in the summer of 1984. It is composed of physicians treating HIV-infected patients, an infectious disease physician, a nurse, social worker, legal counsel, infection control officer, and an administrator. This group deals with relevant issues of policy, procedure and program development.

In March, 1989, the adolescent clinic had its first HIV-positive patient identified in its High Risk Youth—Risk Reduction Program.

HEMOPHILIA COMPREHENSIVE CARE PROGRAM

The hemophilia program was the first at CHLA to recognize and respond to the AIDS problem. The hemophilia team is composed of full- and part-time members, including physicians (infectious diseases, orthopedics, hematology), dentists, two PNPs, two research nurses, social workers, psychologists, a physical therapist, and a physician's assistant. Care for the care-givers is an important concept. From the experience of the hemophilia staff, came the idea of the AIDS Help Prevention Plan (AHPP), offering staff support activities dealing with the psychological impact that HIV has on patients, family, and staff. Part of the AHPP budget includes a peer program. A mental health professional conducts discussion groups with staff, focusing on stress reduction stemming from guilt feelings, and other aspects of working with hemophiliacs diagnosed with HIV infection.

CLINICAL IMMUNOLOGY SERVICE

The CHLA Clinical Immunology Service first identified HIV in children in 1983. Immunology clinic meets five times each week and, on the average, identifies a new patient every two weeks. It has a staff of four: a physician, a PNP, an RN, and a social worker. Psychological consultation is available as needed.

Twice a year the AIDS Treatment Center physicians and PNPs hold an open question and answer forum for all interested hospital employees.

One staff member has developed and edits a quarterly publication entitled *CHLA AIDS Update*; a one-page pamphlet with current information related to HIV/AIDS news, hospital policy/procedures, practice, and research.

RISK REDUCTION PROGRAM

As more adolescents with positive HIV antibody tests were being seen in the adolescent clinic, it became clear that these individuals had a unique set of needs which required special attention from the providers. In March, 1989, the High Risk Youth Project set aside two half days a week for clinical sessions just for this group, and called it the Risk Reduction Program. Adolescents are referred from other community youth-serving organizations and many come on their own after learning about the

new service from the High Risk Youth Project staff and street outreach workers. About five or six youngsters are seen each week with real and perceived risks for HIV exposure. They are counseled, tested and offered further education about the HIV infection. To date, about 12 persons are followed on a regular basis by the risk reduction clinic staff.

SIZE

Over 100 patients and 17 staff members are involved in the CHLA AIDS Treatment Center. They consist of:

- 60 active immunology patients with four staff members
- 45 to 50 hemophilia patients with five full-time and five part-time staff members
- 12 Risk Reduction Program patients with 5 staff members and a total of 45 seen cumulatively in the RRP members.

STRUCTURE

The treatment center is decentralized. Each clinic is funded separately and employs its own staff. For instance, several of the nurses and social workers are employed by hematology/oncology, immunology, and adolescent divisions rather than by the hospital department of nursing or social work.

FINANCES

The Pediatric AIDS Treatment Center grew largely as a result of research and service grants obtained in the three specialty areas. In addition to several federal, state, and foundation grants, the program receives funding from the Los Angeles Pediatric AIDS Network.

Children's Hospital, Oakland, California

HOSPITAL

Children's Hospital Oakland (CHO) is a private, 195-bed hospital. On site there are 171 beds, with a variety of children's health services, supplemented with another 24 beds located in a nearby general hospital.

COMMUNITY

CHO is located in mixed residential-commercial neighborhood near the University of California at Berkeley. It serves an ethnically, racially, and economically mixed population.

EVOLUTION

The first child with AIDS was seen by the infectious disease physicians in 1983. The incidence of HIV infection grew gradually until it became a larger part of the infectious disease practice. In 1986, Ann Petru, MD, began seeking staff and program status for the growing HIV patient population.

In 1987, when the patient census for HIV-infected children reached 16, a full-time clinical nurse coordinator was funded. Six months later, a full-time social work position was funded. By 1988, the number of children being seen at CHO for possible or proven HIV infection more than doubled, to 34, and by the end of 1989 it was 77.

The HIV clinic is held once a week and patients are seen on other days for acute care and extensive initial evaluations. The primary HIV team meets weekly for case conferences and planning. Patients are seen monthly in the infusion unit for administra-

tion of intravenous immunoglobulin therapy, IV study drugs, and transfusions.

The goal of the HIV program is to maintain the HIV-infected child at home by providing support services and accessible ambulatory care. That goal will be accomplished within the framework of the overall program plan to have about half of the patients seen at the CHO clinic and the other half in the community at local primary care pediatricians' offices.

The HIV-infected children with hemophilia continue to receive their primary care in the CHO hemophilia program clinic. The hemophilia program physician, clinical nurse specialist, and social worker maintain a collaborative relationship with the HIV team, consulting as needed.

SIZE

Primary staff of the HIV/AIDS Program includes:

- 1 Infectious disease physician who is the administrative manager
- 1 Nurse coordinator
- 1 Social worker/case manager
- 1 Secretary (part time)
- 1 Research coordinator/nurse

Additional members involved in HIV care are:

- Nutritionists
- Child development specialists
- Pulmonologists
- Neurologists

Patient statistics as of December, 1989 are:

- 77 HIV-positive children have been seen
- 16 of whom have been diagnosed with AIDS
- 6 have died

Families in the HIV/AIDS Program represent a population spectrum from center city, intravenous drug users, to suburban, middle socioeconomic status and heterosexually infected families. Eighty percent of HIV/AIDS program patients live with their families, 85 percent are less than two years of age, and one child was placed in foster care during 1989.

STRUCTURE

Figure 4-9 depicts the organizational structure. The HIV/AIDS Program is organizationally located within the infectious disease division of the department of medicine. The nurse coordinator and

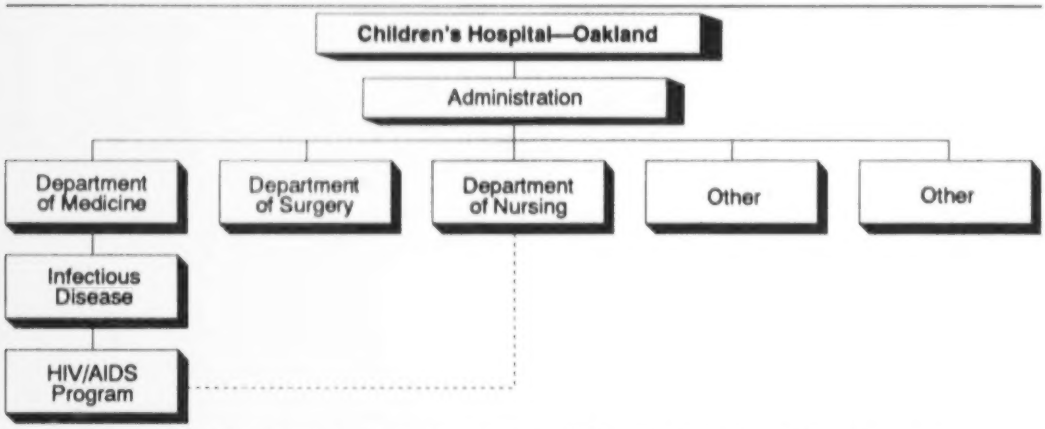

Figure 4-9. Organizational Structure of Children's Hospital—Oakland

social worker are employed and evaluated by the hospital's department of nursing and social work, respectively, and permanently assigned to the HIV program. An interdisciplinary hospital AIDS committee oversees the research and program activity dealing with HIV infection and recommends HIV policy to the medical board. The committee is composed of representatives from the following areas: medicine, nursing, social service, laboratory, medical residents, administration, dietary and housekeeping. Information regarding HIV issues is provided through regular meetings held by the department managers.

FINANCES

In addition to two federal grants—one from the National Institute of Child Health and Human Development, and the other from the National Institute of Allergy and Infectious Diseases—the program is supported by the hospital. □

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1. Hein, K. (1987, May). AIDS in Adolescents: A Rationale for Concern. *New York State Journal of Medicine*, 87, (290), 5.

2. Hegarty, J. D., et. al. (1988, October 7). The medical Care Costs of Human Immunodeficiency Virus-Infected Children in Harlem. *Journal of the American Medical Association*, 260, (13), 1901-1905.

3. Hegarty, 1904.

4. Boland, M., et. al. (1989). Children's Hospital AIDS Program (CHAP). Newark, N. J: United Hospitals Medical Center Foundation.

5. These standards and protocols may be available by early 1990. Contact Anne Warwick, Vice President for Nursing, Mount Washington Pediatric Hospital, Inc., 1708 West Rogers Avenue, Baltimore, Maryland 21209. (301) 578-8600.

EPILOGUE

This overview of ten pediatric HIV/AIDS programs offers only a glimpse into the complex, involved intervention provided. Speaking with persons working in these programs will offer additional insight. Appendix F is listing of addresses and telephone numbers of the programs described in this chapter. Again, the critical program components in Appendix D provide a complete source of services necessary to provide comprehensive care to children with the chronic illness of HIV infection.

Directors and staff of the ten programs cited in this *Sourcebook* have enthusiastically shared their insights, and expressed their willingness to advise others who may be seeking guidance in establishing a program for HIV-infected children in their communities. □

Appendix A

CENTERS FOR DISEASE CONTROL CLASSIFICATION OF PEDIATRIC HIV INFECTION AND INTERNATIONAL CLASSIFICATION OF DISEASES CODES

Classification of Pediatric HIV Infection[1]

Class P-O: Indeterminate infection, includes perinatally exposed infants and children up to 15 months of age who cannot be classified as definitely infected, but who have antibodies to HIV, indicating exposure to a mother who is infected.

Class P-1: Asymptomatic infection includes patients who meet one of the above definitions for HIV infection but who have had no previous signs or symptoms that would have led to classification in Class P-2.

These children may be subclassified on the basis of immunologic testing. This testing should include quantitative immunoglobulins, complete blood count with differential, and T-lymphocyte subset quantitation. Results of functional testing of lymphocytes (mitogens such as pokeweed) may also be abnormal in HIV-infected children, but it is less specific in comparison with immunoglobulin levels and lymphocyte subset analysis, and it may be impractical.

Subclass A — Normal immune function includes children with no immune abnormalities associated with HIV infection.

Subclass B — Abnormal immune function includes children with one or more of the commonly observed immune abnormalities associated with HIV infection, such as hypergammaglobulinemia, T-helper (T4) lymphopenia, decreased T-helper/T-suppressor (T4/T8) ratio, and absolute lymphopenia. Other causes of these abnormalities must be excluded.

Subclass C — Not tested includes children for whom no or incomplete (see above) immunologic testing has been done.

Class P-2: Symptomatic infection includes patients meeting the above definitions for HIV infection and displaying signs and symptoms of infection. Other causes of these signs and symptoms should be excluded. Subclasses are defined based on the type of signs and symptoms that are present. Patients may be classified in more than one subclass.

Subclass A — Nonspecific findings include children with two or more unexplained non-specific findings persisting for more than 2 months, including fever, failure-to-thrive or weight loss of more than 10% of baseline, hepatomegaly, splenomegaly, generalized lymphadenopathy (lymph nodes measuring at least 0.5 cm present in two or more sites, with bilateral lymph nodes counting as one site), parotitis, and diarrhea (three or more loose stools per day) that is either persistent or recur-

rent (defined as two or more episodes of diarrhea accompanied by dehydration within a 2-month period).

Subclass B — Progressive neurologic disease includes children with one or more of the following progressive findings: 1) loss of developmental milestones or intellectual ability, 2) impaired brain growth (acquired microcephaly and/or brain atrophy demonstrated on computerized tomographic scan or magnetic resonance imaging scan), or 3) progressive symmetrical motor deficits manifested by two or more of these findings: paresis, abnormal tone, pathologic reflexes, ataxia, or gait disturbance.

Subclass C—Lymphoid interstitial pneumonitis includes children with a histologically confirmed pneumonitis characterized by diffuse interstitial and peribronchiolar infiltration of lymphocytes and plasma cells and without identifiable pathogens, or, in the absence of a histologic diagnosis, a chronic pneumonitis—characterized by bilateral reticulonodular interstitial infiltrates with or without hilar lymphadenopathy—present on chest X-ray for a period of at least 2 months and unresponsive to appropriate antimicrobial therapy. Other causes of interstitial infiltrates should be excluded, such as tuberculosis, Pneumocystis carinii pneumonia, cytomegalovirus infection, or other viral or parasitic infections.

Subclass D—Secondary infectious diseases includes children with a diagnosis of an infectious disease that occurs as a result of immune deficiency caused by infection with HIV.

Category D-1: Includes patients with secondary infectious disease due to one of the specified infectious diseases listed in the CDC surveillance definition for AIDS: Pneumocystis carinii pneumonia; chronic cryptosporidiosis; disseminated toxoplasmosis with onset after 1 month of age; extra-intestinal strongyloidiasis; chronic isosporiasis; candidiasis (esophageal, bronchial, or pulmonary; extrapulmonary cryptococcosis; disseminated histoplasmosis; noncutaneous, extrapulmonary, or disseminated mycobacterial infection (any species other than leprae); cytomegalovirus infection with onset after 1 month of age; chronic mucocutaneous or disseminated herpes simplex virus infection with onset after 1 month of age;extrapulmonary or disseminated coccidiomycosis; nocardiosis; and progressive multifocal leukoencephalopathy.

Category D-2: Includes patients with unexplained, recurrent, serious bacterial infections (two or more within a 2-year period) including sepsis, meningitis, pneumonia, abscess on an internal organ, and bone/joint infections.

Category D-3: Includes patients with other infectious diseases, including oral candidiasis persisting for 2 months or more, two or more episodes of herpes stomatitis within a year, or multidermatomal or disseminated herpes zoster infection.

Subclass E — Secondary cancers include children with any cancer described below in categories E-1 and E-2.

Category E-1: Includes patients with the diagnosis of one or more kinds of cancer known to be associated with HIV infection as listed in the surveillance definition of AIDS and indicative of a defect in cell-mediated immunity: Kaposi's sarcoma, B-cell non-Hodgkin's lymphoma, or primary lymphoma of the brain.

Category E-2: Includes patients with the diagnosis of other malignancies possibly associated with HIV infection.

Subclass F—Other diseases include children with other conditions possibly due to HIV infection not listed in the above subclasses, such as hepatitis, cardiopathy, nephropathy, hematologic disorders (anemia, thrombocytopenia), and dermatologic diseases.[2]

International Classification of Diseases (ICD-9 Codes)[3]

042 Human immunodeficiency virus infection with specified conditions. Includes acquired immune deficiency syndrome (AIDS)

042.0 With specified infections—includes only (with HIV infection):

Candidiasis of lung	(112.4)
Coccidiosis	(007.2)
Cryptosporidiosis	(007.2)
Isosporiasis	(007.2)
Cryptococcosis	(117.5)
Pneumocystosis	(136.6)
Progressive multifocal leukoencephalopathy	(146.3)
Toxoplasmosis	(130)

042.1 Causing other specified infections (due to HIV infection)

Includes only:

Candidiasis, disseminated of	(112.5)
Mouth	(112.0)
Skin and nails	(112.3)
Other and unspecified sites	(112.8, 112.9)
(excludes: 112.1, 112.2, 112.4)	
Coccidioidomycosis	(114)
Cytomegalic inclusion disease	(078.5)
Herpes simplex	(054)
Herpes zoster	(053)
Histoplasmosis	(115)
Mycobacteriosis, other and unspecified	(031.8, 031.9)
(excludes: 031.0, 031.1)	
Nocardia infection	(039)
Opportunistic mycoses	(118)
Pneumonia:	
NOS	(486)
Viral NOS	(480.9)
Salmonella infections	(003.1 - 003.9)
(except gastroenteritis 003.0)	
Septicemia	(038)
Strongyloidiasis	(127.2)
Tuberculosis	(010-018)

042.2 With specified malignant neoplasms (with HIV infection). Includes only:

Burkitts's tumor	(200.2)
Kaposi's sarcoma	(173)
Immunoblastic sarcoma	(202.8)
Primary lymphoma of the brain	(202.8)
Reticulosarcoma	(200.0)

042.9 Acquired immunodeficiency syndrome unspecified

AIDS with other conditions classifiable elsewhere except as in 042.0 - 042.2

043 Causing lymphadenoptahy (due to HIV infection)

Enlarged lymph nodes	(785.6)
Swollen glands	(785.6)

043.1 Causing specified diseases of the central nervous system (due to HIV infection)

Includes only:

Central nervous system:	
Demyelinating disease NOS	(341.9)
Disorders NOS	(348.9, 349.9)
Non-arthropod-borne viral diseases, other and unspecified	(049.8, 049.9)
Slow virus infection, other and unspecified	(046.8, 046.9)
Dementia:	
NOS	(298.9)
Organic	(294.9)
Presenile	(290.1)
Encephalitis	(323.9)
Encephalomyelitis	(323.9)
Encephalopathy	(348.3)
Myelitis	(323.9)
Myelopathy	(336.9)
Organic brain syndrome NOS	
Nonpsychotic	(310.9)
Psychotic	(294.9)

043.2 Causing other disorder involving the immune mechanism

043.3 Causing other specified conditions (due to HIV infection)

Includes only:

Abnormal weight loss	(783.2)
Abnormality, respiratory	(786.0)
Agranulocytosis	(288.0)
Anemia:	
NOS	(285.9)

(**043.3**, Anemia, cont'd)

- Aaplastic, other and unspecified (284.8, 284.9)
- Deficiency (280 - 281)
- Hemolytic, acquired (283)

Arthritis:
- Pyogenic (711.0)
- Infective (711.0, 711.9)

Blindness or low vision (369)
Blood and blood-forming organs,unspecified disease (289.9)
Cachexia (799.4)
Dermatomycosis (111)
Dermatophytosis (110)
Diarrhea (noninfectious) (558)
(infectious) (009)
Disease or disorder NOS:
- Blood and blood-forming organs (289.9)
- Salivary gland (527.9)
- Skin and subcutaneous tissue (709.9)

Dyspnea (786.0)
Fatigue (780.7)
Fever (780.6)
Gastroenteritis (infectious) (009)
(noninfectious) (558)
Hepatomegaly (789.1)
Hyperhidrosis (780.8)
Hypersplenism (289.4)
Infection:
- Intestinal, ill-defined (009)

Lack of expected physiological development in infant (783.4)
Lleukoplakia of oral mucosa (tongue) (528.6)
Malabsorption, intestinal (579.9)
Malaise (780.7)
Neuralgia NOS (729.2)
Neuritis NOS (729.2)
Nutritional deficiencies (260-269)
Ppneumonitis, lymphoid, interstitial (516.8)
Polyneuropathy (357.0, 357.8, 357.9)
Pyrexia (780.6)
Radiculitis NOS (729.2)
Rash NOS (782.1)
Retinal vascular changes (362.1)
Retinopathy, background (362.1)
Splenomegaly (789.2)
Thrombocytopenia, secondary and unspecified (287.4, 287.5)
Volume depletion (276.5)

043.9 Acquired immunodeficiency syndrome-related complex unspecified: AIDS-related complex (ARC) with other conditions classifiable elsewhere except as in 042.0-043.3

044 Other human immunodeficiency virus infection (excludes HIV infection classifiable to 042 or 043)

044.0 Causing specified acute infections (due to HIV infection). Includes only:
- Acute lymphadenitis (683)
- Aseptic meningitis (047.9)
- Viral infection ("infectious mononucleosis-like syndrome") (079.9)

044.9 Human immunodeficiency virus infection, unspecified
- HIV infection with other conditions classifiable elsewhere except as in 042.0-044.0

795.8 Positive serological or viral culture findings for Human Immunodeficiency Virus (HIV)

References

1. Centers for Disease Control. (1987, April 24.) *Morbidity and Mortality Weekly Report, 36*(15), 93-95.

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3. *International Classification of Diseases, 9th Revision, Clinical Modification* (ICD-9-CM). Third Edition. (1989, March). Washington, D. C: U. S. Government Printing Office, DHHS Publication No. 89-1260. 26-26D, 731.

APPENDIX B

COMMUNITY ASSESSMENT GUIDE
Factors Relevant to HIV

1. Identify specific characteristics of the community that your hospital serves.

Physical Description Area:_____(square miles)

Boundaries:

North
South
East
West

Type: Urban_____Suburban_____Rural_____

Residential (percent of area) _____
Commercial _____
Industrial _____
Agricultural _____
Recreational _____

Terrain:

Climate:

Population Description:

Vital Statistics	COMMUNITY Number/Percent	STATE Number/Percent
Birth Rate (living)		
Death Rate		
-general		
-neonatal		
-infant		
-maternal		

Leading Causes of Death:

- in adults
- in children

Age Distribution: (age group by year)	COMMUNITY Number/Percent	STATE Number/Percent
<1		
1 through 4		
5 through 12		
13 through 19		
20-24		
25-34		
35-44		
45-54		
55-64		
65+		
TOTAL		
Sex/Race Distribution:		
Female/white		
Female/black		
Female/hispanic		
Female/other		
Male/white		
Male/black		
Male/hispanic		
Male/other		

Compare your community and state figures with those of the nation, now and ten years ago, to determine trends. Discuss findings with your local health department statistician.

Financial Description

Major industries and number of employees:

Municipal Budget:	(%)	(Total)
Health		
Welfare		
Police		
Fire		
Education		
Transportation		

Family Income: Mean (for family of 4) _____
Percent Below Poverty _____
Percent At Poverty Level _____
Percent at $12,000-$24,000 _____
Percent at $24,100-$50,000 _____
Percent at $50,100-$100,000 _____
Percent over $100,000 _____

Single Head-of-Household (Number/Percent) _____

Employment Status:	Number	Percent
Employed		
Private Industry		
Service Industry		
Self-Employed		
Public Sector		
Military		
Unemployed		

Educational Environment of the Community

Population's Educational Level:

	Number	Percent
Less than 8th Grade		
High School Graduate		
1 - 3 Years College		
College Graduate		
Postgraduate		

Educational Institutions:

	Public Schools	Private Schools
Grades KG-6		
Grades 7-9		
Grades 10-12		

Special schools _____
Community college _____
Colleges/universities _____

Health profession colleges?
Type(s):

Political description	Community	State	Nation
Political leadership and party (mayor, city council, state-national legislators)			

Current Health Issues

Health Status

——————Communicable Disease Incidence——————
in Children

Disease	Current Case #	# Cases 10 Years Ago
AIDS		
Chlamydia		
Diphtheria		
Encephalitis		
Gonorrhea		
Herpes		
Infectious hepatitis		
Influenza		
Measles		
Syphilis		
Tetanus		
T.B.		
Typhoid		

Health-Related Social Problems:

	Number	Percent of Total
Alcoholism		
Child abuse/neglect		
Drug dependency		
Families on Medicaid		
Families with insurance		
Families with neither		
Homeless families		
Illegitimate births		
Illegal drug use		
Suicide		
Undocumented aliens		

ASSESSMENT: What findings are associated with HIV/AIDS?

2. Identify the resources in the community and assess their adequacy for present and future health and psychosocial needs of children and families with HIV infection.

Community Services: (describe location, service, limits, and awareness of HIV issues)

Police

Fire

Ambulance

Media

Public assistance agencies (health, welfare, child protection, entitlements)

Public transportation to health services (location, frequency, adequacy, etc.)

Housing services (temporary shelter or relocation)

Schools (describe health service and affiliations)

Public

Private

Religious institutions (number, describe services)
Protestant
Catholic
Jewish
Other

ASSESSMENT:

Health Facilities and Services for Children

Ambulatory care facilities: (identify location, number being served and adequacy of service)

Community Health clinics

Group medical practices

Hospital outpatient departments

Physician private offices

Mental Health clinics

Health Department: (describe number and adequacy)

Well child clinics (central or community based)

Pediatric treatment clinics

Pediatric dental clinics

Public Health Nursing Services to
-clinics
-schools
-homebound children

Hospitals: (describe bed capacity, services such as immunology, infectious diseases, hematology, and the adequacy of the services)

Public (with pediatric facilities)

Private general (with pediatric facilities)

Children's hospitals

(Children's hospitals—cont'd)

Specialty (serving children)

Psychiatric

Rehabilitation

Long term care

Hospice

ASSESSMENT:

Health personnel (Identify vacancies in budgeted positions for each discipline or category related to HIV work throughout your community.)

	Budgeted positions	Vacancy (%)
Physicians		
Nurses		
Social workers		
Nutritionists		
Developmental specialists		
Mental health specialists		
Home care workers		

ASSESSMENT:

Appendix C

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Reference

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Appendix D

CRITICAL PROGRAM COMPONENTS THROUGHOUT THE CONTINUUM OF CARE

A. Casefinding—counseling and testing offered to all

B. Primary Health Care—well HIV Positive

1. Prevention
   a. immunization
   b. public education
   c. counseling
2. Detection
   a. screening
   b. casefinding
      1) counseling
      2) referral—linkage with community health and mental health centers.
3. Treatment
   a. medication
   b. counseling—including written guides for children and their families.
   c. nutritional therapy
4. Documentation

C. Acute Care—ill HIV Positive

1. casefinding
2. coordination (care management)
3. community-based services—requires staff with pediatric training/experience
   a. home care—multisystem evaluation of home environment
      1) nursing—assessment of parental coping; anticipatory guidance; developmental stimulation; nutrition therapy, both enteral and transparenteral with care of intravenous lines and oxygen
      2) speech therapy
      3) physical/occupational therapy
      4) personal care assistance
      5) home health aide/homemaker
      6) pharmacist
      7) equipment
   b. day treatment—therapeutic day care, including developmental education; preschool education; health care support with medication administration; parental support; and transportation

   c. early intervention program—including weekly rehabilitation services and comprehensive child development evaluation every six months
   d. home-based hospice care with emotional/supportive care to children, and grief and bereavement counseling for families
4. Collaborative, interdisciplinary health care services*
   a. advocacy—with organizations, within bureaucracy, to maintain family integrity, and to ensure non-discrimination
   b. ambulatory—includes primary health care/education/prevention; episodic/distributive care with monthly physical examinations and interval histories; and linkage to a pediatric AIDS home care unit
   c. hospitalization—diagnostic/intensive/intermediate care, laboratory, and patient records
   d. case management with care planning, coordination, and documentation
   e. counseling
5. Child life support—promotion of growth and development
6. Family health support
   a. home/hospice/foster care
   b. respite assistance
   c. placement services, adoption
   d. legal services
   e. homebound teacher
   f. spiritual counsel
7. Financial assistance—entitlements
8. Research-development
9. Education-prevention
   a. case/patient/family
   b. public in schools/colleges, community groups, and with day/foster care staff
   c. professional—staff development, open seminars
10. Public relations
   a. proactive—paving the way
   b. listening/sensitive/responsive to community

D. Tertiary Health Care

1. Community support for the program
2. Interdisciplinary care team
   a. physical/mental/spiritual care
   b. education
   c. counseling support through bereavement
3. Volunteer program
   a. care/maintenance tasks
   b. developmental stimulation activities
   c. recreation/diversion programs

* Includes: chaplains, child life, developmental specialists, education, medicine, mental health, nursing, nutrition, occupational, physical, respiratory and speech therapy, social work, etc.

Appendix E

RESOURCES FOR SERVICE PROVIDERS

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I. AIDS Clinical Trial Units (ACTU)

California

Cedars-Sinai Medical Center
8700 Beverly Boulevard
Los Angeles, CA 90048
Contact: Leslie Spring (213) 206-6369

Childrens Hospital of LA
4650 Sunset Boulevard
Los Angeles, CA 90027
Contact: Leslie Spring (213) 206-6369

Harbor General UCLA Medical Center
1000 Carson Street
Torrence, CA 90509
Contact: Leslie Spring (213) 206-6369

Kaiser Permanente Medical Center
9449 East Imperial Highway
Downey, CA 90242
Contact: Leslie Spring (213) 206-6369

Kaiser Permanente Medical Group
6041 Cadillac Avenue
Los Angeles, CA 90034
Contact: Leslie Spring (213) 206-6369

Kaiser Permanente Medical Group
1505 North Edgemont Street
Los Angeles, CA 90027
Contact: Leslie Spring (213) 206-6369

Kaiser Permanente Medical Group
13652 Cantara Street
Panorama City, CA 91402
Contact: Leslie Spring (213) 206-6369

LA County Medical Center, USC
1200 North State Street
Los Angeles, CA 90055
Contact: Leslie Spring (213) 206-6369

Long Beach Memorial Medical Center
Atlantic Avenue
Long Beach, CA 90801
Contact: Leslie Spring (213) 206-6369

Martin Luther King, Jr./Drew Medical School
12021 South Wilmington Avenue
Los Angeles, CA 90059
Contact: Leslie Spring (213) 206-6369

Moffitt Hospital
M-601 B
San Francisco, CA 94143
Contact: Eivind Sukkestad (415) 476-6480

Olive View Medical Center
14445 Olive View Drive
Sylmar, CA 91342
Contact: Leslie Spring (213) 206-6369

San Francisco General
995 Potrero Street
San Francisco, CA 94110
Contact: Eivind Sukkestad (415) 476-6480

Stanford University School of Medicine
820 Monte Rosa Dr.
Menlo Park, CA 94025
Contact: Barbara Sullivan (415) 723-5682

University of California at Los Angeles
Medical Center
10833 La Conte Ave.
Los Angeles, CA
Contact: Leslie Spring (213) 206-6369

University of California at San Diego
Medical Center
225 Dickinson St. H 814 H
San Diego, CA 92103
Contact: Candace McIvor (619) 543-6447

District of Columbia

Children's National Medical Center
111 Michigan Avenue, NW
Washington, DC 20010
Contact: Kathy McMahon (202) 745-3495

Florida

University of Miami School of Medicine
1800 NW 10th Ave.
Miami, FL 33125
Contact: Janet Gourley
(305) 548-4445 or 549-6364

Illinois

Children's Memorial Medical Center
2300 Childrens Plaza
Chicago, IL 60614
Contact: Gail Lovato (312) 880-4187,
880-4757, or 880-4000

Maryland

The Johns Hopkins University
600 North Wolfe St.
Baltimore, MD 21205
Contact: Yvette Benjamin
(301) 955-9728 or 955-5201

University of Maryland School of Medicine
655 West Baltimore Street
Baltimore, MD 21201
Contact: Susan Seiden (301) 955-9728

Massachusetts

Boston City Hospital
818 Harrison Avenue
Boston, MA 02118
Contact: Anne Marie Reagan (617) 424-5813,
(beeper) 730-1403, x 4826, or 424-5506

Children's Hospital Corporation
300 Longwood Avenue
Boston, MA 02115
Contact: Kerrie Liebendorfer (617) 735-6832,
Andrea Rubin (617) 735-8198 or 735-7621

New Jersey

Children's Hospital of New Jersey
15 South 9th Street
Newark, NJ 07107
Contact: Bessie Bryant (201) 268-8009
or 269-8273

New York

Albert Einstein College of Medicine
1300 Morris Park Ave.
Bronx, NY 10461
Contact: Sarah Patterson (212) 430-2940

Bellevue Hospital Center
27th Street and First Avenue
New York, NY 10016
Contact: Nagamah Deygoo (212) 340-6426

Beth Israel Medical Center
First Avenue at 16th Street
New York, NY 10003
Contact: Dena Radinsky (212) 420-4175

City Hospital at Elmhurst
79-01 Broadway
Elmhurst, NY 11373
Contact: Dinah Reitman (718) 830-1431,
(212) 241-7823, or (212) 241-7856

Columbia University Babies Hospital
650 West 168th Street
New York, NY 10032
Contact: Anne Gershon
(212) 305-5885 or 305-1556

Harlem Hospital
506 Lenox Avenue
New York, NY 10037
Contact: Anne Gershon (212) 305-5885

Mount Sinai School of Medicine
1 Gustave Levy Place
New York, NY 10029
Contact: Eileen Chusid
(212) 241-3934 or 241-5900

North Carolina

Duke University Medical Center, Box 3089
Durham, NC 27710
Contact: Barbara Lane
(919) 684-6335 or 684-5628

Ohio

Columbus Children's Hospital
700 Children's Drive
Columbus, OH 43205
Contact: Carolyn Sipes (614) 461-2248

Cincinnati Children's Hospital
Elland and Bethesda Avenue
Cincinnati, OH 45267
Contact: Ellen Vigdorth (513) 558-6977

Texas

Baylor College of Medicine
One Baylor Plaza
Houston, TX 77030
Contact: Celine Hanson (713) 798-1319

University of Texas Herman Hospital
6411 Fannin Street
Houston, TX 77030
Contact: Marilyn Doyle
(713) 792-5334 or 792-4703

Methodist Hospital
Houston, TX 77030
Contact: Stephen Greenberg (713) 798-4775

Washington

Children's Hospital and Medical Center
4800 Sandpoint Way NE
Seattle, WA 98105
Contact: Michi Thacker (206) 526-2117

II. Pediatric AIDS Demonstration Projects

A. First Year Grant Cycle—1989

Boston Pediatric AIDS Project
Dimock Community Health Center
55 Dimock Street
Roxbury, MA 02119
Coordinator: Modesto German, MD
(617) 442-8800 or 442-8802

Family AIDS Center for Treatment and Support (FACTS)
239 Oxford Street
Providence, RI 02905
Coordinator: (401) 421-6993

Northern Manhattan Women and Children HIV Demonstration Project
600 W. 168th Street
New York, NY 10032
Cheryl Healton (212) 305-3616

Family AIDS Case Management Program, New York City
330 W. 34th Street, Room 311
New York, NY 10001
Coordinator: Gordon Campbell (212) 790-3163

State-Wide Health Services Network for Children with HIV Infection and Their Families, New Jersey
NJ Department of Health, Special Child Health Services,
CN 364
Trenton, NJ 08625
Coordinator: Ms. Barbara Kern (609) 292-5676

Puerto Rico Pediatric AIDS Demonstration Project
Maternal and Child Health Division, PR Department of Health
Box 70184
San Juan, PR 00936
Coordinator:
Miguel Valencia, MD
(809) 767-0870

Pediatric AIDS Demonstration Project, Georgia
GA Department of Human Services
878 Peachtree Street, NE
Atlanta, GA 30309
Coordinator:
Harry Carr (404) 894-6622

Pediatric AIDS Health Care Demonstration Project, Dade County
University of Miami Departments
of Obstetrics and Pediatrics
P.O. Box 016960
Miami, FL 33101
Coordinator: Jo Nell Efantis
(305) 548-4424

A Model Program for Pediatric AIDS Prevention and Control in Michigan
Office of Maternal and Child Health
Michigan Department of Public Health
3423 North Logan Street, PO Box 30195
Lansing, MI 48909
Coordinator: George Baker, MD
(517) 335-8900

Pediatric AIDS Program in New Orleans
Children's Hospital of New Orleans
200 Henry Clay Avenue
New Orleans, LA 70117
Coordinator: Diane Sasson
(504) 899-9511

Pediatric AIDS Health Care Demonstration Project, Texas
University of Texas Health Science Center
7703 Floyd Curl Drive
San Antonio, TX 78284-7802
Coordinator: Maria Cruz (512) 567-5264

Case Management Demonstration Program, Los Angeles County
Los Angeles Pediatric AIDS Network
c/o Childrens Hospital of Los Angeles
4650 Sunset Boulevard
Los Angeles, CA 90027
Coordinator: Marcy Kaplan
(213) 669-5616

Seattle-King County Pediatric AIDS Demonstration Project
Department of Public Health
110 Prefontaine Place, So. #500
Seattle, Wa 98104
Coordinator: Julie Sarkissian
(206) 296-4673

B. Second Year Grant Cycle—1990

Brooklyn Pediatric AIDS Demonstration Project
Health Science Center at Brooklyn
State University of New York
4500 Clarkson Avenue
P.O. Box 49
Brooklyn, NY 11203
Herman Mendez, MD, (718) 270-1313

Model Comprehensive Health Care Program for Adolescents
Montefiore Medical Center
111 East 20th Street
Bronx, NY 10467
Karen K. Hein, MD
(212) 920-2179

Bronx Pediatric AIDS Consortium
Albert Einstein College of Medicine
1300 Morris Park Avenue
Bronx, NY 10461
William Caspe, MD
(212) 588-7000 x 658

Dallas-Fort Worth Area Pediatric AIDS Health Care Program
University of Texas
SW Medical Center
1935 Motor Street
Dallas, TX 75235
Janet Squires, MD (214) 920-2000

III. Organizations

AIDS Action Council
2033 M Street, NW Suite 801
Washington, DC 20036
(202) 293-2886 FAX (202) 296-1292
Jean Flately McGuire, Tom Sheridan

AIDS Baby Crib (ABC) Quilts
Ellen Ahlgren, Founder, ABC Quilts
Northwood, NH 03261
(603) 942-7778

American Academy of Pediatrics
1331 Pennsylvania Avenue, Suite 721
Washington, DC 20004
(202) 662-7460
Susan Campbell, Chair,
Pediatric AIDS Task Force

American Foundation for AIDS Research (AMFAR)
40 West 57th Street
New York, NY 10019
(212) 719-0033 Donald Moschberger

American Nurses' Association
1101 14th Street, NW, Suite 200
Washington, DC 20005 (202) 789-1800
Donna Richardson,
NORA Pediatric AIDS Task Force

American Public Health Association
1015 Fifteenth Street, NW
Washington, DC 20005
(202) 789-5651
Katherine McCarter, Co-Chair,
Prevention Task Force

Child Welfare League of America, Inc.
440 First St. NW, Suite 310
Washington, DC 20001
(202) 638-2952

Fund for Human Dignity
666 Broadway
NY, NY 10012
Sherrie Cohen (212) 529-1600

Health Resources and Services Administration
Parklawn Building
5600 Fishers Lane
Rockville, MD 20857

1. Bureau of Health Care Delivery and Assistance, Community and Migrant Health Centers Program
   Pat Saloman, MD, AIDS Coordinator
   LaVerne Green
   Room 7A-22, (301) 443-2513

2. Bureau of Health Professions
   Regional AIDS Education and Training Centers
   Cherry Tsutsumida
   Room 4C-03, (301) 443-6364

3. Bureau of Maternal and Child Health
   Office of Maternal and Child Health Pediatric AIDS Service Demonstrations, National Issues of High Priority in Pediatric AIDS, and Hemophilia Treatment Centers
   John J. Hutchings, MD, Assistant Director, Division of Services for Children with Special Care Needs (301) 443-2350
   Irene Forsman, RN, Nurse, Consultant
   Room 9-34 (301) 443-1080

4. Office of Health Facilities
   Long-Term and Intermediate Care Facilities for AIDS Patients, Jack Moss, Director; Paul Murphy, Division of Facilities, Assistance and Recovery, Room 11A-10 (301) 443-0271

5. Office of Special Projects
   AIDS Service Demonstration Projects
   AIDS Drug Reimbursement Program
   Home Health Service Formula Grants
   Subacute Care Demonstrations
   June Horner, Chief, HIV Service
   Operations Branch, Sheila McCarthy
   Room 9A-05, (301) 443-0652

National Association of People with AIDS
2025 Eye Street, NW, Suite 415
Washington, DC 20006
(202) 429-2856
Stephen Beck

National AIDS Network
2033 M Street, NW, Suite 800
Washington, DC 20036
(202) 293-2437

National Association of Protection and Advocacy Systems
220 Eye Street, N.E., Suite 150
Washington, DC 20002
(202) 546-8202
Curtis Decker, Executive Director

National Council of LaRaza AIDS Project
20 F Street, NW 2nd floor
Washington, DC 20001
(202) 628-9600
Norm Lopez

National Health Law Program (1)
2639 S. La Cienega Blvd.
Los Angeles, CA 90034
(213) 204-6010

National Health Law Program (2)
2025 M St. NW, Suite 400
Washington, DC 20036
(202) 887-5310

National Minority AIDS Council
714 G Street, SE
P.O. Box 28574
Washington, DC 20003
Lynelle Johnson
(202) 544-1076

National Network of Runaway and Youth Services, Inc.
1400 Eye Street, N.W., Suite 330
Washington, DC 20005
(202) 682-4114
Jay Coburn, Director

National Organizations Responding to AIDS
2033 M Street, NW, Suite 801
Washington, DC 20036
(202) 293-2886 Lisa Iverson

National Pediatric HIV Resource Center
Children's Hospital AIDS Program
Children's Hospital of New Jersey
15 South Ninth Street
Newark, NJ 07107
(201) 268-8251
FAX (201) 485-7769
Carolyn Burr, Coordinator

Pediatric AIDS Foundation
2407 Wilshire Blvd., Suite 613
Santa Monica, CA 90403
Susan DeLaurentis
(213) 395-9051

Pediatric AIDS Coalition
1331 Pennsylvania Avenue, N.W.
Suite 721 North
Washington, D.C. 20004-1703
(202) 662-7460
Susan Campbell, Chairperson
(800) 336-5475

U.S. Conference of Mayors AIDS Program
1620 Eye Street, NW
Fourth Floor
Washington, DC 20006
(202) 293-7330

IV. Audiovisuals

"A Gift of Time"
Pediatric AIDS Foundation
2407 Wilshire Boulevard
Suite 613
Santa Monica, CA 90403 (213) 395-9051

"An Epidemic of Fear: AIDS in the Workplace"
Videotape
San Francisco AIDS Foundation
333 Valencia Street
P.O. Box 6102
San Francisco, CA 94101
(415) 861-3397

"Eating Defensively: Food Safety Advice for Persons with AIDS"
Videotape: September, 1989/TRT: 14:30
Federal Drug Administration, Office of Public Affairs
Sharan Kuperman (301)443-3220
Centers for Disease Control, National AIDS Information Clearinghouse
P.O. Box 6003
Rockville, MD 20850
1 (800) 458-5231

"Family Planning: Talking About AIDS" Film and posters
The Regional Training Center for Family Planning
Room 802
100 Edgewood Avenue, N.E.
Atlanta, GA 30303
(404) 523-1996

"Pediatric AIDS: A Time of Crisis"
Association for the Care of Children's Health
3615 Wisconsin Ave., NW
Washington, DC 20016 (202) 224-1801

"With Loving Arms" A video to recruit foster parents (18 min)
1989/0-87868-395-5/#3925/$34.95.
Child Welfare League of America
440 First Street, NW, Suite 310
Washington, DC 20001 (202) 638-2952

V. Literature

A Guide for Residential Group Care Providers: Serving HIV-Infected Children. Child Welfare League of America, 1989, Publication # 0-08768-367-4/#3674, $12.95. Order from CWLA, C/O CSSC, P.O. Box 7816, 300 Raritan Center Parkway, Edison, NJ 08818-7816.

AIDS: A Guide for Hispanic Leadership, a 26-page prevention manual for community leaders. Order from Publications Department, COSSMHO, 1030 15th St., NW, Suite 1053, Washington, DC 20005. (202) 371-2100. $2 prepaid, bulk rates available.

AIDS and Health Care: Focus on the Future (1989). A Resource Collection prepared by the AIDS Task Force of the American Society for Hospital Marketing and Public Relations. 840 N. Lakeshore Dr., Chicago, IL 60611. (312) 280-6031 Price $15.00 (non-members).

AIDS: Concepts in Nursing Practice, Gee, G., & Moran, T. A. (1989).. Baltimore, MD: Williams & Wilkins.

AIDS/HIV Experimental Treatment Registry, includes several glossaries and information about the federal clinical trials efforts and licensing of drugs (includes pediatric information). AMFAR, 1515 Broadway, Suite, 3801, New York, NY, 10036.
(212) 719-0033.

AIDS: Trading Fears for Facts. A Guide for Teens, by Karen Hein, MD, Theresa Foy DiGeronimo and the Editors of Consumer Reports Books. ISBN Paperback: 0-89043-269-4 from Consumer Reports Books, Administrative, Editorial, and
Sales Offices
51 East 42 Street, Suite 800
New York, NY 12017.

AIDS Treatment News, a biweekly report chronicling current developments in experimental and alternative treatments and public policy issues (not specific to pediatrics). John S. James, (editor) P.O. Box 411256, San Francisco, CA. 94141. Contact Denny Smith at (415) 255-0588.

Alert, a monthly newsletter about AIDS related legislation, education, research and treatment published by the Universal Fellowship of Metropolitan Community Churches, 5300 Santa Monica Blvd., Suite 304, Los Angeles, CA, 90029.

ATIN (AIDS Targeted Information Newsletter), monthly annotated bibliography of worldwide medical journals with medical and research information published by Williams & Wilkins, P. O. Box 23291, Baltimore, MD, 21203
1 (800) 638-6423.

Being Alive, medical updates and information on current trends in law and AIDS discrimination, a calendar of events, and listings of support groups and AIDS services. 4222 Santa Monica Blvd., Los Angeles, CA 90029.

BETA (Bulletin of Experimental Treatments for AIDS). A publication of the San Francisco AIDS Foundation, Box 6182, San Francisco, CA, 94101, (415) 863-AIDS.

Children With AIDS Newsletter. The Newsletter of the Foundation for Children With AIDS, Inc., 77B Warren Street, Brighton, MA 02135. (617) 783-7300.

Clinical Trials—Talking It Over, an educational pamphlet published by the National Institute of Allergy and Infectious Diseases, for those considering participation in a clinical trial for AIDS/HIV. NIAID, Office of Communications, National Institutes of Health, Building 31, Room 7A32
Bethesda, MD 20892.

Learning AIDS, a compendium of AIDS/HIV educational resource materials listing more than 1700 books, brochures, pamphlets, audiotapes, videotapes, films and instructional programs. Produced by AMFAR, available from R.R. Bowker at (212) 719-0033. $24.95.

Living with AIDS: Perspectives for Caregivers. (1989). Washington, DC: St. Francis Center, 5417 Sherier Place, NW, Washington, DC. 20016 (202) 363-8500. $9.95.
Project CHAMP publications, Children's National Medical Center, 111 Michigan Ave., NW, Washington, DC 20010:

> ***HIV-Important News***, for children under 6 years of age.
>
> ***The ABCs of Talking About HIV with Children***, an overview.
>
> ***When a Child's Test is HIV Positive*** , for newly diagnosed families.
>
> ***When Your Friend has HIV Infection***, for children under 10.

PWA Coalition Newsline, a monthly, grassroots news magazine published by and for people with AIDS and AIDS related conditions, reporting extensively on alternative and experimental therapies, community-based research programs, and outreach/networking activities. Another publication is

Surviving and Thriving with AIDS. Published by the PWA Coalition Inc., 31 West 26th Street, New York, NY, 10010. (212) 532-0290.

Respite News (A Publication of the Texas Respite Resource Network). P.O. Box 7330, San Antonio, TX. 78207-3198

(V. Literature—cont'd)

Responding to the AIDS Crises: Innovations in Child Welfare Services, Anderson, Gary. (1990, winter). Edison, NJ: Child Welfare League. (1990/0-87868-384-4/#3844) $24.95.

Someone at School Has AIDS. (1989). National Association of State Boards of Education, 1012 Cameron St., Alexandria,VA 22314. (703) 684-4000. Price: $5.00 each.

Update: AIDS Products in Development, a quarterly chart of antivirals, immunomodulators, anti-infectives as well as information on diagnostics and vaccine. Published by the Pharmaceutical Manufacturers Association, Communications Division, 1100 15th Street NW, Washington, DC 20005 (202) 835-3400.

VI. Telephone Contacts

Parent and patient education booklets.

Child Welfare League of America
(202) 638-2952
National AIDS Information Clearinghouse
1(800) 458-5231
National Pediatric HIV Resource Center (201) 268-8351

Clinical trials.

National Institutes of Health, AIDS prevention, 1 (800) TRIALS-A (874-2572). Monday through Friday, 9 am-7pm, EST

Drug Hotlines.

Project Inform: 1(800) 822-7422
California Hotline: 1(800) 334-7422

AIDS Hotline (24 hours)
U. S. Public Health Service.

English: 1 (800) 342-7514
Spanish: 1 (800) 342-SIDA

APPENDIX F

Listing of Programs

Adolescent AIDS Program 36
Montefiore Medical Center
111 E. 20th Street
Bronx, New York 10467
(212) 920-2179

Harlem Hospital Center 39
Pediatric AIDS Program
17th Floor
506 Lenox Avenue
New York, New York 10037
(212) 694-4176

Children's Hospital AIDS Program 41
Children's Hospital of New Jersey
United Hospitals Medical Center
15 South Ninth Street
Newark, New Jersey 07107
(201) 268-8273

Mt. Washington Pediatric Hospital 45
1708 West Rogers Avenue
Baltimore, Maryland
21209-4596
(301) 578-8600

Children's National Medical Center 46
Special Immunology Service
111 Michigan Avenue, N.W.
Washington, DC 20010
(202) 745-3340, or
745-3495

South Florida AIDS Network 48
Pediatric AIDS Health Care
Demonstration Project
Department of Pediatrics, University
of Miami, P. O. Box 016960
Miami, Florida 33101
(305) 547-5832

Maternal Infant Center for HIV (MICH) 50
Children's Hospital of Michigan
3901 Beaubien Boulevard
Detroit, Michigan 48102
(313) 745-0108

Children's Memorial Hospital, Chicago 52
The Children's Memorial Medical
Center, 2300 Children's Plaza
Chicago, Illinois 60614
(312) 880-3718

Los Angeles Pediatric AIDS Network 54
C/O Childrens Hospital of Los Angeles
4650 Sunset Blvd., P.O. Box 5400
Los Angeles, California 90027
(213) 669-2489

Children's Hospital, Oakland 56
747 Fifty Second Street
Oakland, California 94609
(415) 428-3336

about NACHRI...

The National Association of Children's Hospitals and Related Institutions (NACHRI) is the only national organization of children's hospitals in the country. NACHRI's mission is to promote the well-being of children through support of children's hospitals and related institutions committed to excellence in child health care. It accomplishes this mission through advocacy, the dissemination of information, research and education, and other activities of value to children and the institutions which serve them.

NACHRI was founded in 1968 by 25 children's hospitals. Today NACHRI's membership exceeds 100 hospitals in the U.S. and Canada. Most members are free-standing hospitals providing a wide range of services from primary to tertiary care. Other members of equal excellence are associated with university hospitals or dedicated to specialty needs of children. Virtually all members are teaching hospitals.

Chairman: Jon E. Vice

President: Robert H. Sweeney

Vice President: Mary Gorman

Additional copies of *Children With HIV/AIDS: A Sourcebook for Caring* are available for $7.50 each.

NACHRI
401 Wythe Street
Alexandria, VA 22314
(703) 684-1355

NACHRI

National Association of Children's Hospitals and Related Institutions
Alexandria, Virginia